Peer mentoring for Acquired brain InjuRy Study (PAIRS)

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Abstract

Acquired brain injury (ABI) is an enormous societal problem, and survivors experience lifelong physical, cognitive, and social difficulties. The aim of this PhD was to develop, pilot, and evaluate a peer mentoring intervention, which matched people with experience of living with brain injuries to recent survivors to help them adapt to the effects of their injuries.

The project consisted of three studies: 1) a systematic review of ABI peer mentoring; 2) Patient and Public Involvement and Engagement (PPIE) workshops and qualitative interviews and focus groups to explore the perspectives of ABI survivors, carers, and professionals; and 3) a mixed methods, before-and-after study investigating the feasibility of delivering the peer mentoring intervention.

The systematic review identified eight studies. There was limited quantitative evidence for effectiveness, and the studies highlighted numerous logistical challenges. However, there was qualitative evidence of positive impacts on mentees and mentors. The PPIE workshops and qualitative interviews and focus groups identified a strong perceived need for peer mentoring.

Drawing on the findings of the first two studies, I developed a peer mentor training programme and peer mentoring intervention. I recruited participants via local rehabilitation services, brain injury charities, and university research networks. Nine people completed the mentor training, and four mentees were matched to trained mentors. The four pairs agreed to an introductory meeting and six independent meetings over three months for ABI-related discussions and activities. Carers of three of the mentees were also recruited to assess carer burden and five healthcare providers from the recruitment sites were interviewed regarding recruitment and the delivery of peer mentoring. The effectiveness of the intervention was assessed by pre-intervention and post-intervention measures of participation, quality of life, mood, hope for the future, carer burden, and goal attainment. Post-intervention qualitative interviews explored the participants' experiences of the intervention.

Two pairs met independently six times, one pair met twice, and one once. The quantitative results indicated no clear improvements for the mentees. Post-intervention, all mentees recorded poorer scores for home integration compared to baseline and two deteriorated for anxiety. The carers all showed a reduction in carer burden. The qualitative interviews showed that participants valued social contact with someone impartial. Three mentees were dissatisfied, citing their mentor's lack of common experience due to different ABI types. The mentors derived satisfaction from mentoring. The healthcare providers said that clinicians may be reticent to refer patients for peer mentoring.

In conclusion, delivering a peer mentoring intervention is challenging and resource intensive. The benefits of peer mentoring appear to be difficult to measure quantitatively and the measures used in this study may not have assessed the appropriate factors. There is a need for further studies, although it is not feasible to conduct a large RCT using the methods employed here. There is a need for economic evaluations and investigations into how to implement peer mentoring within/alongside NHS and third sector services.

Declaration

I declare that this thesis has been written solely by myself. I have worked in collaboration with others on some aspects of the data collection and analysis work described, as explicitly stated in the text. Some of the data collected from the stroke interviews and focus groups described in Chapter Three were used for the MSc dissertations of two students who assisted me (Amelia Beveridge and Asweeni Jansdin Raj).

Richard Morris

Impact of COVID-19

The COVID-19 pandemic in early 2020 had an impact on the final delivery of this project. The government restrictions meant that it was necessary for me to move home, causing disruption to the data analysis, writing, and final data collection processes. Although most data had been collected, I had not yet conducted interviews with healthcare providers. All communication and interviews with the healthcare providers had to be conducted over Microsoft Teams. I was unable to meet face-to-face with my supervisors, so all meetings were conducted on Teams. The isolation that was imposed by the lockdowns at a time when I was analysing data and interpreting the implications of my findings made the final stages of the project challenging. I was unable to discuss the project with fellow students, interact regularly with my supervisors, or present my findings at conferences and events and receive feedback. These factors potentially had an impact on the presentation and interpretation of the findings.

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Many thanks to my primary supervisor Professor Kate Radford for all her guidance, patience, and support. Thanks also to my other supervisors Dr Shirley Thomas and Professor Neil Coulson for their invaluable help and encouragement, and to Dr Joanna Fletcher-Smith, who was my supervisor in the first year, was instrumental in securing funding for the studentship, and was my co-reviewer on the systematic review (helping to screen papers for inclusion and conduct data extraction).

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The support and advice of my divisional colleagues was a major help and reassurance in the early days of the study. Dr Julie Phillips (an occupational therapist and researcher) in particular was always there for advice and support and assisted me in preparing and delivering the mentor training. Patricia Dziunka, the divisional administrator, provided invaluable help with organising the mentor training and the expert panel workshops.

My thanks also go to the following people for their contributions to the project: Dr Kate Allatt for helping to fund the project and for allowing us to use her network of stroke survivors to recruit qualitative interview participants; Professor Chris Burton, Implementation Research Fellow at the University of Bangor, for facilitating the expert panel workshops and for sharing his

experiences on a stroke peer coaching project; Dr Patricia Masterson-Algar, who led the Bangor stroke peer coaching study and shared preliminary findings in an expert panel workshop and an interview for this project which were extremely helpful in designing my intervention; The professionals and TBI survivors who gave their time to attend the expert panel workshops; Amelia Beveridge, who conducted the interviews with stroke survivors; Asweeni Jansdin Raj, who helped me to deliver the focus groups with ABI survivors; Blanca De Dios Perez, who assisted me with the post-intervention qualitative interviews and analysis; Headway Nottingham, for allowing us to conduct the focus groups with service users at their day centre; The clinical staff at the recruitment services, for their helpfulness, positivity, and enthusiasm for the project, especially to the managers who gave their time to provide me with invaluable information in the post-intervention interviews; and Dr Andrea Venn, Medical Statistician, for her invaluable advice at the School of Medicine Statistics Advice Clinic.

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Publications and Dissemination

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Sue Watson Postgraduate Oral Presentation Event, October 17th, 2018. Peer mentoring for Acquired brain InjuRy Study (PAIRS). Presentation to the School of Medicine students and judging panel. Winner of 3rd Prize.

Neuropsychology Special Interest Group, Nottinghamshire Healthcare NHS Foundation Trust, Specialist Services Directorate, June 12th, 2018. Peer mentoring for Acquired brain InjuRy Study (PAIRS). Presentation to a regional group of neuropsychologists.

Medicine and Health Sciences Faculty Postgraduate Research Forum, June 28th, 2017. Economic, Societal, and Academic Impact of Peer Mentoring for Acquired Brain Injury.

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Abbreviations and Acronyms

A&E: Accident and emergency

ABI: Acquired brain injury

AMED: Allied and Complementary Medicine Database

ASSIA: Applied Social Sciences Index and Abstracts

ATP: Adenosine triphosphate

BCW: Behaviour change wheel

BIAA: Brain Injury Association of America

BRAIN Initiative: Brain Research through Advancing Innovative Neurotechnologies

BSI: Brief Symptom Inventory

CBS: Caregiver Burden Scale

CDSR: Cochrane Database of Systematic Reviews

CENTRAL: Cochrane Central Register of Controlled Trials

CES–D: Centre for Epidemiological Studies Depression Scale

CHART: Craig Handicap Assessment and Reporting Technique

CHART–SF: Craig Handicap Assessment and Reporting Technique–Short Form

CIM: Community Integration Measure

CIQ: Community Integration Questionnaire

CMR: Cochrane Methodology Register

COM–B: Capability Opportunity Motivation–Behaviour

COREQ: Consolidated Criteria for Reporting Qualitative Research

CPSO: Community peer support officer

CT: Communication tool

CT scan: Computerised tomography scan

CTE: Chronic traumatic encephalopathy

DARE: Database of Abstracts of Reviews of Effects

DASS–21: Depression, Anxiety and Stress Scale, 21 item version

DBS: Disclosure and Barring Service

DCHS: Derbyshire Community Health Services

DNA: Deoxyribonucleic acid

DRS: Disability Rating Scale

EBIQ: European Brain Injury Questionnaire

ED: Emergency department

EED: NHS Economic Evaluation Database

EQ–5D–5L: EuroQol Group Quality-of-Life instrument – 5 level version

EU: European Union

FAD: Family Assessment Device

GABA: Gamma-aminobutyric acid

GCS: Glasgow Coma Scale/Score

GCSE: General Certificate of Secondary Education

GHQ–12: 12–item General Health Questionnaire

GSE: General Self-Efficacy Scale

HCP: Healthcare professional

HHI: Herth Hope Index

HIV: Human immunodeficiency virus

HPW: Hours per week

HRA: Health Research Authority

HTA: Health Technology Assessment database

ICD-10: International Classification of Diseases – Version 10

ICF: International Classification of Functioning Disability and Health

ICP: Intracranial pressure

ID: Identification

IPA questionnaire: Impact on Participation and Autonomy

ISEL: Interpersonal Support Evaluation List

ISRCTN: International Standard Randomised Controlled Trial Number

IT: Information technology

ITS: Interrupted time series analysis

LOC: Loss of consciousness

LSA: Life Space Assessment

LSS: Life Satisfaction Survey

MCMC: My Care My Call

MeSH: Medical Subject Headings

MHS: Miller Hope Scale

MMAT: Mixed Methods Appraisal Tool

MOS: Medical Outcomes Survey

MPAI: Mayo-Portland Adaptability Inventory

MRC: Medical Research Council

MSc: Master of Science postgraduate degree

mTBI: Mild traumatic brain injury

NA: Not applicable

NHS: National Health Service

NUH: Nottingham University Hospitals

OBIA: Ontario Brain Injury Association

OT: Occupational therapist

PAIRS: Peer mentoring for Acquired brain InjuRy Study (PAIRS)

PAM: Patient Activation Measure

PANAS: Positive and Negative Affect Scale

PCT: Personal construct theory

PIC: Participant identification centre

PICO-S tool: Participants, Intervention, Comparator, Outcomes and Study design

PHC: Peer health coach

PHQ: Patient Health Questionnaire

PMQ: Peer Mentoring Questionnaire/Questions

PPIE: Patient and Public Involvement and Engagement

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PTA: Post-traumatic amnesia

QMC: Queen's Medical Centre

QOL: Quality of life

R&D: Research and Development

R&I: Research and Innovation

RCT: Randomised controlled trial

REC: Research Ethics Committee

RTA: Road traffic accident

RTC: Road traffic collision

SAI: Social Activity Interview

SCI: Spinal cord injury

SD: Standard deviation

SDT: Self-determination theory

SET: Self-efficacy theory

SLT: Speech and language therapist

SMAST: Short Michigan Alcohol Screening Tests

SPSS: Statistical Product and Service Solutions

SRS: Supervision Rating Scale

SUCCESS: Success in College after Concussion with Effective Student Supports

SUPERB: SUpporting wellbeing through PEeR-Befriending feasibility trial

SWLS: Satisfaction with Life Scale

TBI: Traumatic brain injury

TBI–MPP: Traumatic Brain Injury-Mentoring Partnership Programme

TIA: Transient ischaemic attack

TIDieR: Template for Intervention Description and Replication

TPB: Theory of planned behaviour

UCLA Loneliness Scale: University of California, Los Angeles Loneliness Scale

UK: United Kingdom

USA: United States of America

VAS: Visual Analogue Scale (of EQ–5D–5L)

VR: Vocational rehabilitation

WHO: World Health Organisation

WhOM: Wheelchair Outcome Measure

WheelCon: Wheelchair Use Confidence Scale

WQLI: Wisconsin Quality-of-Life Inventory

WST-Q: Wheelchair Skills Test Questionnaire

YQOL: Youth Quality-of-Life Instrument

Timeline and Structure of the Project

This PhD consisted of several elements, some of which were conducted in the year prior to the PhD as part of a project on which I worked as a research assistant. I was assisted on some elements of the project by colleagues and students of my chief supervisor. This section is intended to assist the reader's understanding of the structure and timeline of the project and the roles of the people involved.

The timeline ends with the post-intervention assessments and does not include the subsequent writing of the thesis, which was entirely my own work.

Peer coAching foR parTICIPation AfTEr traumatic brain injury (PARTICIPATE) project (July 2015–June 2016): This project was conducted in the year preceding the PhD. It was a small study funded by the Slater & Gordon Health Projects and Research Fund to conduct preliminary work into the development of a peer coaching intervention for people with TBI. The term 'peer coaching' was subsequently replaced in the PhD project by 'peer mentoring', and the concept of support for traumatic brain injury survivors was broadened to include all forms of acquired brain injury.

This project was created by my chief supervisor, and I was employed as a research assistant. The elements outlined below were subsequently used as part of the PhD. The elements provided information on the need for peer mentoring and helped to inform the development of the intervention model.

Date	Study element	Purpose	People involved
June–July 2015	Expert panel workshops.	To gain the perspectives of brain injury survivors, and professionals in health and social care, rehabilitation, sports, and legal services on the design of a peer mentoring intervention. To identify the advantages and disadvantages of peer	Professor Kate Radford (supervisor) and Dr Julie Phillips (research occupational therapist and divisional colleague) – Concept, planning, and delivery. Mrs Patricia Dziunka (divisional administrator) – Administration.

		mentoring and discuss logistical issues. Used in the PhD Patient and Public Involvement and Engagement (PPIE) study presented in Chapter Three.	Professor Chris Burton (Implementation Research Fellow, Bangor University; co-author of a peer coaching after stroke study) – workshop facilitator.
July–October 2015	TBI survivor telephone interviews.	To elicit brain injury survivors' views regarding the impact of brain injury on social and leisure participation and the advantages and disadvantages of peer mentoring. Used in the PhD qualitative study presented in Chapter Three.	Prof Kate Radford and Dr Julie Phillips – Concept, planning, and original topic guide. Patricia Dziunka – Administration. I conducted all the interviews except one, which was conducted by Dr Phillips. This was because the interviewee requested a face-to-face interview with a female interviewer. I developed the topic guide from the original devised by Prof Radford and Dr Phillips.
PhD Study: Peer mentoring for Acquired brain InjuRy Study (PAIRS) (July 2016–Autumn 2019): The PhD was funded when the PARTICIPATE project came to an end.			
Study One: Systematic Review (Chapter Two)			
Autumn 2016 and updated in Autumn 2022	Systematic review of ABI peer mentoring.	To identify evidence regarding peer mentoring for ABI.	I was assisted in the screening and selection of the studies and data extraction by Dr Joanna Fletcher-Smith (supervisor during year one of the PhD). The review was updated in Autumn 2022 by Dr Blanca

			De Dios Perez (post-doctoral researcher in the division under the supervision of Prof Radford), using the search strategies devised by me. Dr De Dios Perez was the primary author of the published paper of the review, with me as a co-author.
Study Two: Focus Groups and Qualitative Interviews (Chapter Three)			
June 2017	Focus groups with ABI survivors.	To understand the views of ABI survivors regarding the need for peer mentoring, the issues involved in its delivery, and the barriers and facilitators to social and leisure participation after brain injury.	Asweeni Jansdin Raj, MSc Rehabilitation student at UoN, helped with the organisation and delivery of the focus groups and with topic guide design. Asweeni was a volunteer at a local Headway day centre, so was able to facilitate the focus groups there. Asweeni used the data for her MSc dissertation.
July 2017	Interviews with severely impaired stroke survivors.	To understand the views of stroke survivors regarding the need for peer mentoring, the issues involved in its delivery, and the barriers and facilitators to social and leisure participation after severe strokes.	These were conducted by Amelia Beveridge (another MSc student under the supervision of Prof Radford), who used the data for her MSc Rehabilitation project. The topic guides were jointly designed by me and Amelia. The participants were recruited with the assistance of Dr Kate Allatt through her network of stroke survivors.

October–November 2017	Interviews with service providers.	To understand the views of ABI professionals regarding the need for peer mentoring and the key issues involved in its delivery.	I conducted all the interviews. I designed the topic guides with feedback from my supervisors.
October–November 2017	Interviews with carers.	To understand the perspectives of carers regarding the importance of peer mentoring and the key issues involved in its delivery.	I conducted all the interviews. I designed the topic guides with feedback from my supervisors.
Study Three: Peer Mentoring Intervention (Chapters Four and Five)			
Summer 2018–Spring 2019	Recruitment.	Recruiting mentors and mentees to participate in the intervention.	Participants were recruited with the assistance of Nottinghamshire and Derbyshire community ABI rehabilitation services and ABI charities.
January 2019	Mentor training.	To train, screen, and select mentors for the intervention.	The training days were designed by myself based on information gathered in the systematic review and the PPIE and qualitative work. Feedback and input from Professor Kate Radford and Dr Julie Phillips. Dr Phillips attended the training sessions, provided assistance as required, and helped me to assess the participants' suitability as mentors.
Spring 2019	Preintervention quantitative assessments.	Baseline assessments for comparison with postintervention repeat measures.	I conducted all the baseline assessments myself at participants' homes.

Spring and Summer 2019	Peer mentoring meetings.	Mentors meeting with mentees in the community.	I attended introductory meetings with the participants, who subsequently met unsupervised. Participants contacted me before and after meetings to ensure their safety.
Autumn 2019	Postintervention quantitative and qualitative interviews.	Quantitative assessment of changes in the measures. Qualitative assessments of participants' experiences of the peer mentoring intervention.	I conducted all the quantitative interviews by telephone. The qualitative interviews were conducted by Dr Blanca De Dios Perez, a divisional researcher who was then a PhD student also supervised by Prof Radford. Dr De Dios Perez also assisted me with the analysis of the data as part of the framework analysis process.

1 Chapter One: Introduction

1.1 Aims and Objectives of the PhD

The overall aim of this PhD was to design a peer mentoring intervention for ABI survivors and to investigate the feasibility of delivery and implementation. The secondary aims were to determine whether the intervention was associated with changes in participation and other outcomes identified as important and relevant to peer mentoring. To achieve these aims the PhD consists of three studies, each with specific objectives. These are outlined in the table below, along with the thesis chapter in which they are presented.

Table 1.1. PhD programme and thesis structure overview.

Study	Overall aim	Objectives	Chapter
Systematic review	Informing intervention design	Identify the current evidence for the design and effectiveness of peer mentoring for ABI.	Two
Stakeholder engagement and qualitative study	Informing intervention design	Explore the perspectives of ABI survivors, carers, rehabilitation providers, researchers and peer mentoring providers regarding the design, delivery, logistical issues, and key outcomes of peer mentoring.	Three
Pre- post-feasibility study	Investigating the feasibility of delivery and implementation	Recruit mentors and mentees; train mentors; establish pairings; operationalise the intervention; measure changes in participation and other outcomes identified in the first two studies; explore the perspectives of participants and healthcare providers on the intervention; identify logistical challenges and solutions.	Four and five

1.2 Chapter One Summary

The thesis will begin in Chapter One with background which will outline the need for peer mentoring for people with ABI. This will begin by discussing the human brain, the anatomy and physiology of the different forms of brain injury, and the incidence and prevalence of these conditions. I will then explain the consequences of injury, its impact on individuals and society, and the current approaches to rehabilitation. This will lead onto the background and rationale for peer mentoring as a promising intervention for people with brain injuries.

1.3 The Brain

The brain is wider than the sky,

For, put them side by side,

The one the other will include

With ease, and you beside

- Emily Dickinson, c. 1862 (Dickinson, 1960)

The average human brain weighs about 1.2–1.4 kgs (Hartmann et al., 1994; Kandel and Pokharel, 2022), consists mainly of water, fat and protein, and has the consistency of softened butter (Bryson, 2019). It never makes direct contact with the world, sitting in the dark of the skull, does not move or pulse, and appears to do nothing at all. Unsurprisingly, throughout most of human history it was considered unimportant. Only in the last few hundred years have we come to realise that the brain is the most extraordinary object we know of in the universe, responsible for everything we do, feel and know, as individuals

and as a civilisation (Carter, 2014). Each brain is precious and vulnerable, and injury has catastrophic consequences.

The human brain consists of approximately 86 billion neurons, 86 billion glial cells (Herculano-Houzel, 2012; von Bartheld et al., 2016) and trillions of synaptic connections, as many connections "in a single cubic centimetre of brain tissue as there are stars in the Milky Way" (Eagleman, 2012). There are innumerable connective loops, and each region is linked to many others in enormously complex networks (Sporns, 2011; Sporns et al., 2005; Yeh, 2022). Some functions are localised in specific regions of the brain, so damage to a certain area will cause specific impairment (Haas, 2001; Keller et al., 2009). However, neurons only microns apart can have completely different jobs, so identical injuries can have very different effects with only slight changes in location (Hawryluk and Manley, 2015). The brain is too complex to allow us to stratify location and function in any simplistic way.

In fact, we still have limited understanding of how the brain works. The sheer scale of the problem of understanding the brain and the consequences of injury can be understood when considering the achievements of recent international brain mapping projects, such as the US BRAIN Initiative (Insel et al., 2013) and the European Commission's Human Brain Project (Markram et al., 2011; Markram, 2012; Amunts et al., 2016). These are exciting initiatives, but despite huge government funding over many years they are still nowhere closer to mapping the whole human brain or to finding any link between specific neural pathways and aspects of human behaviour (Abbott, 2021; Mullin, 2021). As we are no closer to a true understanding of the mind, to being able to repair the brain, or reverse the effects of injury, it is vital that we find new ways to help

people whose lives have been changed by brain injury (Maas et al., 2017; 2022). The challenges described in the following sections demand new, innovative, and individualised approaches to rehabilitation, such as the one investigated in this study.

1.4 Pathophysiology and Epidemiology of ABI

Acquired brain injury (ABI) is an umbrella term used to describe damage to the brain that is not congenital or perinatal (Campbell, 2004). ABIs are traumatic injuries or single-event pathologies, but not degenerative or progressive neurological diseases (such as multiple sclerosis) (Campbell, 2004). The principal causes of ABI are traumatic brain injuries (TBI); strokes; hypoxia from heart attacks, drowning, electrocution or anaesthetic accidents; tumours; meningitis; encephalitis; hypoglycaemia; and cerebral abscesses (Turner-Stokes et al., 2015).

This section will briefly outline the physiological mechanisms of the main forms of ABI: TBI, stroke, and hypoxic–ischaemic injury. The section will also touch on elements of other forms, such as infections. In so doing, I hope to demonstrate the immense complexity of ABI, the difficulty of treatment, the scale of the problem, and the importance of rehabilitation.

1.4.1 Traumatic Brain Injury

There are many differences in the way TBIs are classified and reported in different countries and regions. Epidemiological studies use different methodologies, with some extrapolating from small samples of patients from single hospitals (Parsonage, 2016). This method does not provide an accurate picture, because head injury rates vary widely between regions depending on

population demographics and prevalent risk factors in the society, such as public transport use and rates of violent crime (Brazinova et al., 2016). Other studies have employed long-term follow up of birth cohorts, but these have produced dramatically variable results (Winqvist et al., 2007; McKinlay et al., 2008). It is important to provide standardised data which capture the true incidence of TBI as accurately as possible. One method of doing this is by using the International Classification of Diseases (ICD-10) diagnosis codes (recently superseded by ICD-11, which was adopted in January 2022) for hospital admissions. These show that there were 158,255 admissions to UK hospitals for head injuries in 2019–20, with an incidence rate of 237 per 100,000 (NHS Digital, 2022; Headway - the brain injury association & Health and Social Care Information Centre, 2022). Admissions for males are approximately 1.6 times higher than for females, with 94,575 male admissions in 2019–20 compared to 63,670 females. International studies which used similar methodology have estimated the global incidence of TBI in 2016 to be from 27 million (James et al., 2019; Feigin et al., 2019) to 69 million (Dewan et al., 2018). These figures greatly underestimate those with minor head injuries, many of whom do not report to a hospital, but do have ongoing problems after injury (Tennant, 2005). The most common causes of TBI in England are falls (50%), assaults (16–17%), road traffic collisions (7–8%), and being struck by objects (8%) (Headway - the brain injury association & Health and Social Care Information Centre, 2022). Falls and road traffic collisions are also the most common causes of TBI globally (James et al., 2019).

Accurate data for prevalence are even more difficult to ascertain and require mathematical modelling based on incidence rates. The best estimates suggest

that that the number of people living with the effects of TBI worldwide is 55.5 million, with 382,000 in the UK (James et al., 2019). This UK figure is likely to be a significant underestimate, and other, older studies have put the figure at over one million (Tennant, 2005). Recent estimates have quantified the financial cost in health resources and lost productivity in the UK to be £15 billion for TBI (Parsonage, 2016).

TBI is defined as "an alteration in brain function, or other evidence of brain pathology, caused by an external force" (Menon et al., 2010). TBI has immensely complex pathophysiology and primary and secondary mechanisms by which it can cause damage (Prins et al., 2013; Maas et al., 2017; Ghajar, 2000; Masel and DeWitt, 2010; Prasetyo, 2020). Primary damage occurs at the time of the injury, whereas secondary damage evolves over the subsequent minutes, hours, days, weeks, or even years (Maas et al., 2017; Ghajar, 2000). The primary injury can be either 'impact', when the head makes direct contact with an object, or 'non-impact', from rapid acceleration and deceleration, or from a force such as blast waves (Prins et al., 2013). These events lead to focal injuries in the area that was struck, and diffuse injuries, spread out over a broader area (McAllister, 2011).

Primary injury mechanisms include contusions, compression, rotation, shearing, laceration, contrecoup injury (in which the brain bounces back and forth in the skull and injury occurs on the opposite side to the impact), penetrating injury (when the object penetrates the skull and makes direct contact with the brain), and diffuse axonal injury, in which nerve cells suffer widespread tearing and microbleeds (Prasetyo, 2020; Payne et al., 2019). The primary injury then leads to secondary complications, which cause further

damage. A bruised brain swells inside the skull, raising intracranial pressure (ICP) and crushing other areas of the brain (Maas et al., 2017; McAllister, 2011). Blood flow is restricted, blockages can occur, and brain regions are deprived of oxygen, causing hypoxic/anoxic injury (Maas et al., 2017). Haemorrhages can occur which cause bleeding (haematomas) inside the brain, further increasing the damage and ICP (Maas et al., 2017).

In the acute phase after TBI (up to one hour) there is a massive, indiscriminate release of the neurotransmitter glutamate (Prins et al., 2013; Prasetyo, 2020; McAllister, 2011). This triggers a cascade of chemical reactions which rapidly depletes the brain cells' energy stores and prevents the cells from firing normally. The subsequent chemical imbalance in the brain leads to a further sequence of reactions which cause permanent damage to cells. Uptake of glucose, the brain's primary fuel source, is compromised for days or even weeks, causing further cell death and damage as the cells' energy requirements are not met (Prins et al., 2013). There is an increased level of free radicals (molecules with unpaired electrons) in the brain after injury because the normal cellular mechanisms that regulate them are unable to function (O'Connell and Littleton-Kearney, 2013). These free radicals damage cell membranes, proteins, and DNA (O'Connell and Littleton-Kearney, 2013). These and other physiological responses to brain injury are interdependent, with cascades of neurochemical and metabolic processes interacting and influencing each other in immensely complex ways (Farkas and Povlishock, 2007).

The complexity of the brain's pathology, the type, intensity, direction, and duration of the external forces involved, and individual factors such as age and gender, mean that no two TBIs are the same (Hawryluk and Manley, 2015).

We still do not fully understand how the mechanisms of secondary cellular injury operate in humans, because research at the acute stage is difficult. Most of our knowledge comes from studies in rats, whereas the processes in humans are different and far more complex. Therefore, there has been limited progress in acute treatments and management (Maas et al., 2017).

Conventionally, TBIs are categorised as minor (or mild), moderate, and severe, according to the Glasgow Coma Scale (GCS) score (Teasdale and Jennett, 1974; Teasdale and Jennett, 1976). Minor head injury is classed as a GCS of 13–15, moderate injury a GCS of 9–12, and severe injury < 9. These classifications are important to aid prognosis, treatment provision, and to categorise participants in research studies. However, meaningful classification is challenging because presentation can range along a continuum from slight disorientation, to protracted loss of consciousness and coma (Maas et al., 2017). GCS is considered by some to be flawed and outdated, and methods of categorising severity are inconsistently applied (Green, 2011; Hawryluk and Manley, 2015). Despite these limitations and inconsistencies, TBI research populations are still grouped together according to their injury severity, even though those in the same categories may all have radically different types of injury and effects (Maas et al., 2017).

The impact of TBI on the individual reaches far beyond the acute injury and sequelae. It is well-established that TBI survivors have a much higher rate of epilepsy than the general population, and it is estimated that TBI accounts for about 5% of all cases of epilepsy (Annegers et al., 1998; Hauser et al., 1991). TBI survivors have a higher mortality rate and lower life expectancy than age and gender matched people without TBI (Haagsma et al., 2016; Masel and

DeWitt, 2010). There also is evidence that TBI is a major risk factor for neurodegenerative disorders such as dementia (Sayed et al., 2013; Shively et al., 2012) and Parkinson's disease (Jafari et al., 2013; Gardner et al., 2015). Repeated concussions are recognised as causing a distinct pathology referred to as chronic traumatic encephalopathy (CTE) (McKee et al., 2016; Bieniek et al., 2021). This is increasingly being recognised as a catastrophic problem in high impact sports such as American football, soccer, rugby union, and rugby league (Kaup and Yaffe, 2017; Deshpande et al., 2017; Dave et al., 2022; Mooney et al., 2020; Russell et al., 2022; Pearce et al., 2018; Yakoub et al., 2018). Contrary to previous beliefs, there is evidence that TBI survivors experience ongoing cognitive decline several years after injury (Wood, 2017; Newcombe et al., 2016), and also that TBI is a risk-factor for stroke (Burke et al., 2013; Liao et al., 2014).

1.4.2 Strokes

There were 137,403 (206 per 100,000 of population) admissions to hospital for strokes in the UK in 2019–20, including 71,280 males (216 per 100,000) and 65,848 females (195 per 100,000) (Headway - the brain injury association & Health and Social Care Information Centre, 2022). The global annual incidence of stroke is estimated at 13.7 million (Feigin et al., 2019). The worldwide prevalence for stroke has been estimated in recent studies at 80.1 million (Johnson et al., 2019) and 104.2 million (Avan et al., 2019), while the economic costs of stokes have been calculated at £8.9 billion per year in the UK (Saka et al., 2009) and €64 billion in Europe in the year 2010 (Gustavsson et al., 2011). Stroke is the second leading cause of death globally after ischaemic heart disease, killing 5.5 million people per year in recent estimates

(Kuriakose and Xiao, 2020). Stroke is widely regarded as the most common cause of complex disability (Adamson et al., 2004).

A stroke is a sudden loss of neurological function caused by interference with the blood supply to the central nervous system. Strokes are characterised by blockages or ruptures of blood vessels within or leading to the brain, which kill brain cells due to lack of oxygen (Kuriakose and Xiao, 2020). The brain has a huge demand for oxygen and energy, which are supplied by the blood, so maintaining an efficient blood supply to the brain is critically important (Purves D, 2001). This is especially important because neurons are more sensitive to oxygen deprivation than other types of cells, so die quickly when the oxygen supply is lost (Mir et al., 2014). The two main ways the supply can fail are from blockages in the blood vessels, and from damage to the walls of the vessels which cause them to bleed (NHS, 2022b). Blockage is called ischaemia and leads to ischaemic strokes (Musuka et al., 2015), while bleeding is called haemorrhage and leads to haemorrhagic strokes (Mir et al., 2014).

Approximately 85% of strokes are ischaemic (Kuriakose and Xiao, 2020) and ischaemic strokes are further subdivided into two groups, thrombotic and embolic (Mir et al., 2014). Thrombotic strokes are caused by a clot that has formed within a blood vessel because of a condition called atherosclerosis, in which an artery becomes thickened by fatty plaque and narrows, causing blood flow to slow down (Grory et al., 2021). When a clot forms it can fully occlude the artery and prevent any more blood getting through. An embolic stroke is caused by a clot or other material that travels from elsewhere in the body and gets stuck in a blood vessel in the brain, blocking the blood flow (Ntaios and Hart, 2017). Whatever the cause of the blockage, ischaemia causes

neurological damage by several pathological mechanisms, many of them similar to the mechanisms of TBI (Mir et al., 2014).

Lack of oxygen causes necrosis (cell death) to a core region, while an area surrounding this may also be partially injured. Necrosis is followed by damage to the membranes of the affected cells, the leaking of cellular contents, and inflammation (Mitsios et al., 2006). This triggers a cascade of neurochemical responses resulting in excessive neurotransmitter release (particularly glutamate), excess production of free radicals, protein damage, and cell death (Malarkey and Parpura, 2008). Damage to cells in blood vessels also disturbs the blood–brain barrier and potentially allows dangerous molecules to enter the brain (Kassner and Merali, 2015).

The other 15% of strokes are haemorrhagic strokes (Kuriakose and Xiao, 2020), which happen when blood vessels in the brain rupture and bleed (NHS, 2022a). This can occur either within the brain (intracerebral haemorrhage) or in the membranes (meninges) that surround it (subarachnoid haemorrhage) (Mir et al., 2014). The abnormal accumulation of blood presses against tissue, increases pressure in the brain, restricts the provision of nutrients and oxygen to the neurons, causes inflammation, further neurochemical responses, and cell death (Testai and Aiyagari, 2008). Haemorrhagic strokes are usually caused by high blood pressure, burst aneurysms (weak spots in the walls of blood vessels), vascular malformations, or bleeding disorders (Unnithan et al., 2022). The severity of strokes and the damage caused depend on the location and the amount of bleeding.

The acute treatment of stroke relies on restoring the blood and oxygen supply to affected cells as quickly as possible to limit the damage (Rudd, 2016; Testai and Aiyagari, 2008; Zerna et al., 2018). Most research into neuropharmacological interventions has relied on animal studies because, as with TBIs, it is extremely difficult to conduct acute research with humans (Zerna et al., 2018; Maas et al., 2017; Kuriakose and Xiao, 2020). Preventing neuronal death has been a key goal for research, but with limited success due to the complexity and unpredictability of the neurochemical chain reactions at work (Cramer et al., 2017; Lin et al., 2018). Glutamate receptors, GABA agonists, and sodium channel blockers have all proved ineffective in trials (Hoyte et al., 2004; Ginsberg, 2008; Choi, 2020). The role of free radicals in cell death after stroke means that reducing the levels of free radicals would be a step towards finding a treatment. However, this is complex, and, while damaging if uncontrolled, free radicals are critical for normal cellular and vascular function (Margaill et al., 2005; Schaller, 2005). Inflammation causes increased damage, but is also a critical response to injury; therefore, trials to reduce inflammation have failed to show clinical benefit (Shirley et al., 2014; Antonic et al., 2018). The most widely used clinical approach is the administration of thrombolysis drugs to break up clots causing ischaemic strokes. This has been shown to be effective, but safely providing the treatment requires early identification of the type of stroke (Wardlaw et al., 2014; Bray et al., 2013; National Institute for Health and Care Excellence, 2019).

1.4.3 Hypoxic Brain Injury

There were 1,463 admissions to hospitals in England in 2019–20 for primary anoxic brain injury (Headway - the brain injury association & Health and

Social Care Information Centre, 2022). However, the incidence and prevalence rates of hypoxic/anoxic brain injuries are impossible to calculate with any accuracy, because hypoxic brain injury can result from a wide variety of conditions and injuries, including primary brain injuries. For example, post-cardiac arrest brain injury is the main cause of death in patients resuscitated after cardiac arrest and is the main cause of long-term disability in those who survive (Sandroni et al., 2021). Given that there are approximately 30,000 cardiac arrests outside hospital annually in the UK, with a survival rate of around 1 in 10 (Hawkes et al., 2017), it is reasonable to assume that approximately 3,000 people per year sustain post-cardiac arrest brain injuries in the UK. A great many more people also sustain hypoxic brain injury from the variety of other causes discussed below.

Hypoxic brain injury is caused by reduced oxygen availability to the brain (Hrishi et al., 2019). Specifically, hypoxia refers to reduced oxygen availability, whereas anoxia means the complete absence of oxygen, but the terms tend to be used interchangeably. Due to its high metabolic demand the brain is extremely susceptible to damage from oxygen deprivation (Busl and Greer, 2010). As described above, this can happen to brain tissue because of TBI and stroke. It can also be caused by cardiac arrest; cardiac failure secondary to massive blood loss, traumatic or septic shock; heart conditions such as myocardial infarction; drowning; strangulation; tracheal compression or obstruction; and carbon monoxide poisoning (Busl and Greer, 2010; Hrishi et al., 2019).

The mechanisms of injury are different for each type of hypoxia. Reduced blood flow leads to ischaemia at vulnerable vascular border zones distant from

the major cerebral arteries (Cervos-Navarro and Diemer, 1991; Hendrikse et al., 2008). Brain regions with high metabolic demands, such as the hippocampus, cerebellum, basal ganglia, and cortex, are also particularly vulnerable (Cervos-Navarro and Diemer, 1991). Conversely, the cells of the brain stem are resistant to prolonged hypoxia, so can survive after severe hypoxic damage to the rest of the brain, leading to vegetative states (Brady et al., 2005). Damage at a cellular level is progressive and follows many similar mechanisms to those in action after TBI and stroke. The lack of oxygen to the cells causes the depolarisation of cell membranes, changes in electrolyte composition, mitochondrial damage, and reduced production of ATP, causing reduced energy production and cell death (Xie et al., 1995; Nguyen et al., 2018). Dead tissue triggers an inflammatory response, swelling, an accumulation of waste products, and excessive amounts of the excitatory neurotransmitter glutamate and free radicals, which cause further destruction of cells (Xie et al., 1995; Goldberg and Choi, 1993). A partial return of oxygen supply can then trigger further responses (reperfusion injury), such as free radical production and further glutamate release, which cause a protracted secondary process of neuronal damage (Kloner et al., 2018).

Mild sustained hypoxia, such as typically happens with carbon monoxide poisoning, presents as confusion, inattentiveness, short-term memory loss, and impaired motor skills (Hrishi et al., 2019). The vulnerability of the hippocampus (which is crucial for short-term memory consolidation), and the basal ganglia and cerebellum (which control co-ordinated movement), means that impairments of memory and motor skills are common (Petito et al., 1987; Wolstenholme and Moore, 2010). Brief but severe anoxia can cause seizures

and loss of consciousness, while prolonged and severe oxygen deprivation can cause global destruction of neurons, resulting in deep comas and vegetative states (Jacinto et al., 2001; Sandroni et al., 2021).

1.4.4 Bacterial Meningitis and Encephalitis

There were 5,102 admissions to hospitals in England for diagnoses of meningitis in 2019–20 and 3,628 for encephalitis (Headway - the brain injury association & Health and Social Care Information Centre, 2022), whereas global admissions have been calculated at 2.8 million for meningitis and at 6.5 million for encephalitis (Feigin et al., 2019). The disparity in the ratios here is likely to be due to differences in the ICD-10 codes included. Again, we do not know how many people sustain lasting brain injury due to these conditions, but the vulnerability of the brain to these common viral and bacterial infections means there are undoubtedly many thousands in the UK.

Similar mechanisms are at work after meningitis and encephalitis as those involved after TBIs, strokes, and hypoxia. For example, the response of the immune system to insult is heavily involved in secondary brain injury after TBIs, strokes, and hypoxia. While this response is essential to eradicating dangerous pathogens, it also causes inflammation, neurochemical cascades, and the destruction of neurons (Prins et al., 2013; O'Connell and Littleton-Kearney, 2013; McAllister, 2011). Similar mechanisms are initiated after neurological viruses and immune conditions such as bacterial meningitis and encephalitis (in its vast number of forms) (Barichello et al., 2016; Heckenberg et al., 2014; Hoffman and Weber, 2009). In bacterial meningitis, bacteria cross the normally impenetrable blood–brain barrier and replicate in the subarachnoid space surrounding the brain, releasing damaging pathogens

(Sharief et al., 1992; Heckenberg et al., 2014). Viral encephalitis is caused by a wide range of viruses which manage to cross the blood–brain barrier and enter the nervous system (Kelley et al., 2017). The immune system responds by attacking the pathogens, but this causes inflammation which increases intracranial pressure and damages neurons by causing chain reactions of excitatory glutamate release, free radical production and unregulated protein synthesis (Bravo-Oro et al., 2015). Autoimmune encephalitis involves antibodies, which are intended to remove pathogens, attacking the brain in error, usually after being produced in response to other pathogens or tumours (Kayser et al., 2013).

1.4.5 Incidence of Other Conditions

The variety of possible causes of ABI means it is not possible to discuss the pathophysiology of them all here. However, it should be noted that in English hospitals in 2019–20 there were 37,315 admissions for brain tumours, 3,505 for hydrocephalus, and over 5,000 for other disorders such as encephalopathy and abscesses (Headway - the brain injury association & Health and Social Care Information Centre, 2022). In total, there were 358,699 admissions for ABI-related diagnoses. Of course, not all these people have ongoing problems, but a significant number do, and many more sustain undiagnosed minor head injuries which cause protracted post-concussion symptoms (Hou et al., 2011). Furthermore, many people have primary diagnoses of cardiac arrests and extracranial injuries, but also have brain injuries which are undiagnosed. All these people are not included in the statistics that are cited for brain injuries.

It is also important to remember for the purposes of this thesis that ABI affects a high proportion of young people who have a lot of their lives left to live and a

lot of time to fill. In 2019–20 there were 53,733 head injury admissions for people of working age in England (Headway - the brain injury association & Health and Social Care Information Centre, 2022). This includes 49,841 people aged under 40. Stroke also affects a lot more young people than is commonly imagined, with 31,034 admissions for people of working age in 2019–20, including 3,519 people aged under 40.

1.4.6 Summary of Sections 1.3 and 1.4

The previous sections have attempted to portray ABI as not just an umbrella term for a set of unrelated conditions. Rather, it is an immensely complex disease with a multitude of causes, all of which cause damage to the brain via similar mechanisms. However, despite the similarities, the complex, interconnected nature of these mechanisms, and the complexity of the brain, mean that no two ABIs are ever the same.

ABI is a vast, insufficiently recognised, global public health concern. Accounting for the varying and conservative estimates of the prevalence of TBI, stroke and the other ABIs cited above, it is likely that there are at least two million ABI survivors in the UK and 150 million worldwide. A significant number of those people are young, and their lives are changed dramatically by the effects of their injuries. I will now go on to discuss the myriad ways ABI affects people and impacts on their lives and those around them.

1.5 Sequelae of ABI

People with ABI experience a huge variety of impairments, depending partly on the nature and location of the injury, but also on a range of other factors. There are physical, cognitive, communicative, behavioural, psychosocial, and

environmental problems which present in diverse ways at each level (Turner-Stokes et al., 2015; Mohamed Ludin and Abdul Rashid, 2020; Pavlovic et al., 2019; Wilson et al., 2017; Fleminger and Ponsford, 2005). Each individual experiences a unique combination of these impairments, which result in limitations and restrictions on activities (the impact of impairments on things the person likes to do) and participation (the impact of activity limitations on a person's place in society), as defined by the World Health Organisation International Classification of Functioning (WHO ICF) (World Health Organization, 2002).

Some impairments limit a person's physical ability to perform activities (Ponsford et al., 2014b). Movement in hands, arms, and legs can be affected, which causes difficulties with walking, moving around, and performing tasks (Lerdal et al., 2011). Some people cannot pick things up, make dinners, or go to the toilet by themselves (Craig et al., 2011). Spasticity, weakness, paralysis, and balance problems are also common (Sunnerhagen et al., 2019). People may be unable to participate in sports and exercise activities and their health, fitness, and social lives are detrimentally affected as a result (Palstam et al., 2019; de Graaf et al., 2018; Goverover et al., 2017; Larsson et al., 2013). Fatigue is also a common problem, and this can exacerbate other issues (Cantor et al., 2013; Ponsford et al., 2012). Fatigue can be caused by sleep problems, which are often an issue after ABI, but can also be related to other factors, such as reduced cognitive capacity and energy reserves (Jonasson et al., 2018; Cumming et al., 2018; Penner and Paul, 2017; Ponchel et al., 2015; Bushnik et al., 2015; Ponsford and Sinclair, 2014).

Brain injury affects the ability to think, process and retain information (Rabinowitz and Levin, 2014; Pavlovic et al., 2019; Ponsford et al., 2014b; Pearce et al., 2018; Jonasson et al., 2018; Azouvi et al., 2017; Whyte et al., 2011; Hoogman et al., 2007). Short-term memory can be severely impaired, meaning people cannot remember appointments, forget they have left the oven on, or cannot keep track of conversations (Baldwin et al., 2011; Fish et al., 2007; Azouvi et al., 2017). Long-term memory loss means people forget aspects of their lives, such as people, places and important events, which can cause terrible anxiety, depression, and loss of self-identity (Stracciari et al., 2008; Vickery et al., 2005; Vakil, 2005). Short-term memory loss also severely restricts the ability to live a fulfilling, meaningful life (Nys et al., 2006). Concentration problems mean people cannot process and retain information or focus on completing tasks (Kreutzer et al., 2001; Ponsford et al., 2011) and complex problem-solving may be impossible, as can enjoyment of activities such as watching TV, watching films, and reading (Andelic et al., 2009; Mohamed Ludin and Abdul Rashid, 2020). Reasoning, insight, empathy, multi-tasking, initiation, and task-switching can all be difficult or impossible (Robertson and Schmitter-Edgecombe, 2015; Smeets et al., 2014; FitzGerald et al., 2012; Pavlovic et al., 2019; Barman et al., 2016; Rabinowitz and Levin, 2014).

Any aspect of sensory function can be affected. There can be complete loss, partial loss, or changes to sight (Greenwald et al., 2012; Sand et al., 2013; Suter, 2017), hearing (Munjal et al., 2010; Bamiou, 2015), taste and smell (Drummond et al., 2013; Dutta et al., 2013), touch (Carey et al., 2018), vestibular awareness (Franke et al., 2012; Kolev and Sergeeva, 2016), and

visual–perceptual skills (Martinaud, 2017; Humphreys and Riddoch, 2013). These can be caused by physical or cognitive impairments, the result of damage to the sensory organs or of damage to the parts of the brain responsible for processing sensory information. For example, people with visual agnosia can have completely functional eyesight but be unable to recognise specific categories of objects or faces (Humphreys and Riddoch, 2013; Martinaud, 2017; Corrow et al., 2016; McNeil and Warrington, 2013). People with visual or spatial neglect are unable to process or attend to stimuli from one side (usually the left side, resulting from damage to the right brain hemisphere) (Esposito et al., 2021; Ting et al., 2011). These people may deny that the left side of their own body exists or state that their left leg belongs to somebody else (Jenkinson et al., 2013; Berti and Rizzolatti, 1992).

The physical and cognitive effects of brain injury can affect people's ability to communicate and comprehend (Douglas, 2021). Physical injury may impair speech, while cognitive deficits can mean people cannot understand, remember, or concentrate on what is being communicated to them (Dijkers, 2004). Other aspects of communication can be directly affected by damage to specific areas of the brain. Aphasia is a language-specific disorder caused by injury to regions of the brain which specialise in the expression and communication of language (Brady et al., 2016; Thiel and Zumbansen, 2016). People with expressive aphasia have difficulty finding words and may be completely unable to speak coherently, while those with receptive aphasia may be unable to interpret words (Sreedharan et al., 2020; Croquelois and Bogousslavsky, 2011). These conditions can occur completely without

impairment of cognitive capacity, so a person with aphasia may know exactly what they want to say but be unable to express the words.

People with ABI can have difficulty moderating emotions and behaviour. Depression and anxiety are common (Longworth et al., 2018; Chun et al., 2018; Scholten et al., 2016; Jorge et al., 2004), while there can also be extremes of emotion, dramatic mood changes, and corresponding behavioural problems, such as aggression or violence (Wood and Thomas, 2013; Arciniegas and Wortzel, 2014). People can lose the ability to inhibit impulses (Osborne-Crowley and McDonald, 2018), while there is often the converse inability to initiate action, leading to inertia and apathy (Worthington and Wood, 2018; Starkstein and Pahissa, 2014). Perseveration and obsessiveness lead to inability to stop doing certain things or thinking certain thoughts (Mallya et al., 2014). All these problems impact on people's participation in social situations and roles. Personal interactions can be difficult or embarrassing and there can be problems in employment and relationships (Larsson et al., 2013).

Personality can change dramatically after brain injury, with people becoming very different in their moods, interests, responses, sense of humour, social interactions, and general demeanour (McAllister, 2011). This can lead to changes or breakdowns in relationships and can also cause great strain and distress to family members who feel like the person they love has gone (Bodley-Scott and Riley, 2015).

All these problems can change people's pre-injury relationships and impair their abilities to make new relationships. They may have difficulties with

looking after children; moving around independently; carrying out everyday activities; cooking; eating; maintaining personal hygiene; shopping; housework; driving; using public transport; using the phone; using a computer; corresponding by telephone or email; filling in forms; looking after personal finances; participating in enjoyable leisure activities; staying fit and healthy; interacting with people socially and professionally; obtaining and maintaining employment; pursuing education; and controlling their personal environment (Palstam et al., 2019; Douglas, 2019; Goverover et al., 2017). Brain injury impairs confidence and self-esteem; can destroy the sense of self as a consistent person; remove people's feeling of place in the world; and take away control of the future, personal destiny, autonomy, hope, and ambition (Ponsford et al., 2014a).

Brain injury also changes the lives of partners and family members, who may suddenly become 'carers' (Bodley-Scott and Riley, 2015). The changes to the person they loved have an enormous emotional and psychological impact. They find themselves living with a stranger and coping with their mood swings and aggression. There can be depression and anxiety, resentment, changes in lifestyle, loss of social and leisure activities, loss of social life, loss of health and fitness, loss of household earnings, reduced working hours or loss of employment, reliance on welfare benefits, increased household costs, and more time spent caring for children (Rickardsson et al., 2022; Chan et al., 2009).

1.5.1 Summary of Section 1.5

The effects of brain injury are innumerable. Every impairment of physical, cognitive, emotional, and behavioural function interacts with each other. Each problem exacerbates others and lives and relationships are transformed in ways

both large and small. As there is no way to repair the brain and reverse the damage, rehabilitation becomes key to adapting to the injury. In the next section I will discuss brain injury rehabilitation and its objectives.

1.6 Rehabilitation for ABI

Rehabilitation services have the difficult task of meeting each ABI survivor's unique combination of challenges. In practice, different people need different programmes of rehabilitation, and the same person will require different programmes at different stages of recovery (Turner-Stokes et al., 2015). During the initial stages, particularly after severe injuries, people may require intensive in-patient rehabilitation to return them to functional independence and transition from the hospital back to the community (Turner-Stokes, 2009b; Barman et al., 2016). When a person is back living at home, rehabilitation needs to focus more on social integration, employment, participation, and psychosocial adjustment (Turner-Stokes et al., 2015). Brain injury rehabilitation services are typically multi-disciplinary and include input from clinical neuropsychologists, occupational therapists, social workers, nurses, physiotherapists, speech and language therapists, dietitians, and rehabilitation consultants (Turner-Strokes, 2003).

There are huge disparities in the rehabilitation provided for each individual. Early neurorehabilitation has been shown to be effective yet the provision of resources across the UK is inconsistent and often inadequate (Menon and Bryant, 2019; Barnes et al., 2018). Numerous guidelines exist (Turner-Stokes, 2009b; Turner-Strokes, 2003; Rudd, 2016; Scottish Intercollegiate Guidelines Network, 2013; Scottish Intercollegiate Guidelines Network, 2010), yet implementation of them is often poor and the use of rehabilitation prescriptions

is inconsistent or non-existent (Barnes et al., 2018; Menon and Bryant, 2019). Provision of rehabilitation tends to be time-limited, so people only receive services for typically six months to one year (Barnes et al., 2018). Therefore, it is often left to charities and independent services, such as Headway, the Stroke Association, and the Encephalitis Society, to provide long-term support (Barnes et al., 2018).

Part of the problem is that rehabilitation is difficult to define or describe and is different for different people. A recent editorial examined information from systematic reviews in order to find key features and develop an empirical definition (Wade, 2020). The conclusions were that rehabilitation must "optimise a person's self-rated quality of life and degree of social integration through optimising independence, minimising pain and distress, and optimising the ability to adapt and respond to the changes in circumstances." (Wade, 2020). Crucially, it was concluded that rehabilitation can "benefit anyone with a long-term disabling illness at any stage of that illness" and "be delivered in any setting." (Wade, 2020). This is vital to consider, as we think about how to help brain injury survivors who are living back in the community to adapt to their new lives.

One key goal of rehabilitation is participation. Guidelines state that explicit arrangements should be put in place for the timely provision of on-going rehabilitation, which should focus on improving participation and societal integration, including support for purposeful activities such as leisure and voluntary work (Turner-Stokes, 2009b). However, as the next section will show, rehabilitation for participation is a difficult concept and better approaches are needed.

1.7 Participation

Participation is a notoriously difficult concept to define. It is at the core of bio-psychosocial models of disability according to the World Health Organisation (WHO), whose International Classification of Functioning, Disability and Health (ICF) defines participation as “involvement in a life situation” (World Health Organization, 2002). The ICF provides a powerful conceptual framework to explain and describe multiple aspects of illness and disability, and to understand the sequalae of ABI in the everyday contexts they occur.

The ICF was developed by the WHO to provide a pragmatic framework for the description and classification of functioning and disability. It provides a common language for health, functioning, disability, impairments, and limitations. The ICF is a biopsychosocial model, which allows impairments to be viewed within the context of an individual’s environment (Wade and Halligan, 2003). It is a classification of health and health-related domains, which help to describe changes in body function and structure, what a person can do in a standard environment (capacity), and what they actually do in their lived environment (performance). The ICF is important because it presents a way of viewing ‘health’ and ‘disability’ as part of a continuum, or spectrum, on which everybody fits. Therefore, everybody can experience some degree of health impairment, and some level of limitation to activity, which presents a restriction on participation. The emphasis is therefore on health and functioning, rather than on ‘disability’ (Rudd, 2016).

The framework is articulated in terms of the following:

- Pathology (the disease process).

- Impairment (symptoms/signs: the manifestation of the condition on the individual).
- Activities (the impact of impairment on the person's usual activities).
- Participation (the impact of activity limitations on a person's place in family and society) (Rudd, 2016).

While early interventions are aimed at the pathology of ABI and at limiting the extent of physical damage, later interventions, such as the one trialled in this project, seek to modify the impact of impairment on the person's activities and participation.

Participation in enjoyable and meaningful leisure activities is vitally important for subjective well-being in the general population (Kuykendall et al., 2018). After brain injury, it is an important factor in life-satisfaction, quality of life (QOL), well-being and social integration, particularly for those unable to return to work (Malley et al., 2007; Wise et al., 2010; Bier et al., 2009). Unfortunately, studies have shown that only 19%–50% of TBI survivors achieve pre-injury levels of participation in leisure activities within twelve months of injury (Bier et al., 2009; Wise et al., 2010; Fleming et al., 2011) and fewer than half at ten years post-injury (Ponsford et al., 2014b). Studies with stroke survivors have also shown persistent restrictions in activities of daily living, leisure and community activities (Hartman-Maeir et al., 2007; de Graaf et al., 2018; Elloker and Rhoda, 2018; Palstam et al., 2019).

A Swedish study attempted to discover the factors affecting participation after traumatic brain injury (Larsson et al., 2013). The study (n = 63) examined patient perspectives of participation four years after TBI by administering the European Brain Injury Questionnaire (EBIQ), EuroQol-5D, Swedish Stroke

Register Questionnaire, and Impact on Participation and Autonomy (IPA) questionnaire (Cardol et al., 2001). The results showed that 40% of respondents reported problems on most areas of the EBIQ, and between 20% and 40% reported poor participation on items of the IPA. Logistical regression revealed five items on the EBIQ which were predictive of up to 70% of the variation in participation; 'lack of interest in your surroundings'; 'losing contact with your friends'; 'others do not understand my problems'; 'thinking only of myself'; and 'failing to notice other people's mood'. All these items suggest that a self-centred orientation and disconnectedness from others are strongly related to reduction in participation; areas which interventions can attempt to improve. Another recent study in the USA compared past and present levels of activity participation between 52 community-dwelling TBI survivors and 30 healthy age-matched controls (Goverover et al., 2017). Participants completed cognitive tests rating executive function, auditory/verbal learning, depression, health-related quality of life, and activities they participated in currently and before their injury, or currently and ten years previously for controls. Results showed that participants post-TBI had significantly reduced activities in most areas of life, particularly in social activities, high demand leisure activities and household activities. TBI participants had significantly lower current activity levels than controls. TBI participants' levels of participation were significantly related to age, time since injury, and health-related quality of life, with participation levels decreasing more with longer time, higher age and lower health-related quality of life.

These studies were conducted in different countries with different social contexts to the UK. In addition, they were also quite small samples and only

one study used a control group. Nevertheless, they do provide evidence for decreased participation and increased social isolation after brain injury, and interesting perspectives on the associated factors. There is also no reason to think that the results of studies with TBI participants cannot be extrapolated to other forms of ABI, considering the similarities previously discussed.

1.7.1 Summary of Sections 1.6 and 1.7

The increased isolation, lack of activity, associated loss of meaning in life, negative, self-oriented thinking, depression and reduced quality of life are very concerning when we consider the lack of support provided to so many ABI survivors. The fact that rehabilitation can be so hard to come by, short-lasting, and lacking in government funding means that innovative, sustainable, cost-effective, low-resource interventions are required to help people lead connected, fulfilled, and personally meaningful lives. Importantly, connection with others and feeling understood and listened to are key predictors of participation and also integral aspects of the intervention in this project.

1.8 Peer Mentoring

While healthcare professionals have medical expertise, people with brain injury have experience of living with the condition which can be useful to help others (Levy et al., 2021). Peer support is a popular intervention after brain injury and many other forms of disability. It often takes the form of support groups meeting on an informal basis, sometimes run by rehabilitation services but more often by third sector organisations such as Headway at their day centres and the Stroke Association at Stroke Clubs (Glover, 2003). Another form of peer support which has become increasingly popular in recent years is peer

mentoring, which takes place on a one-to-one basis. Peer mentoring is defined as a relationship between two individuals who share characteristics or experiences, where one provides support to the other (Sherman et al., 2004) and offers a "positive example of someone who has experienced the same or similar situation/issues" (Money et al., 2011, p.6). Another way to understand the concept is by looking at the two elements of the term separately:

'Peer': One that is of equal standing with another.

'Mentor': An experienced and trusted advisor.

(Concise Oxford English Dictionary).

So, a peer mentor can be defined as an experienced and trusted advisor who is of equal standing with their mentee. Peer mentoring "has great potential for providing assistance to individuals struggling with challenging life experiences, such as in cases where someone has acquired a new disability" (Hayes and Balcazar, 2008).

Peer mentoring has been associated with decreased feelings of loneliness, enhanced social competence, acceptance of chronic conditions, reduced feelings of isolation and fear, social validation and empowerment in studies of conditions such as spinal cord injury(Veith et al., 2006; Balcazar et al., 2011), HIV (Rotheram-Borus et al., 2011), diabetes (Goldman et al., 2013), coronary heart disease (Turner et al., 2012), cancer (Rini et al., 2006) and musculoskeletal pain (Matthias et al., 2015). It has been identified as an important form of peer support for military veterans, including those with TBIs, with the particular advantages of offering individual attention and advocacy (Money et al., 2011). Peer mentoring may be particularly

advantageous for some ABI survivors, who may not live near a group or be able to access transport; they may lack motivation to attend; be unable to organise their time adequately; be physically unable; or struggle to cope with new people or noisy group environments (Money et al., 2011).

The aim of peer mentoring, or any other form of social intervention, is to change people's attitudes and behaviours in a positive way. Theories and models of human behaviour can help to inform the design of such interventions and help us to understand the mechanisms by which they can bring about change. The following section outlines some of the theories connected to peer mentoring research.

1.9 Psychological Theories of Behaviour Change

Recent research into peer mentoring for people with ABI or spinal cord injury (SCI), as described in Section 1.10 below, makes use of a range of theoretical perspectives. These theories can help to inform greater understanding of the mechanisms by which peer mentoring can help people to adapt to life with a brain injury. One such perspective is transformational leadership theory (Bass, 1985; Bass and Riggio, 2006). Transformational leadership involves a leader, for example, a teacher, manager, or mentor, "moving the follower beyond immediate self-interests through idealised influence (charisma), inspiration, intellectual stimulation, or individualised consideration" (Bass, 1999, p.11). Researchers have suggested that a peer mentor can use transformational leadership qualities to support their partner (Beauchamp et al., 2016; Shaw et al., 2018; Masterson-Algar et al., 2020).

Other theoretical perspectives attracting interest in the SCI literature are self-efficacy theory (SET) (Bandura, 1977) and self-determination theory (SDT) (Deci and Ryan, 1985; Ryan and Deci, 2000). SET states that the key factors in behaviour change are confidence in the ability to carry out an action (self-efficacy) and expectation that a goal will be achieved (outcome expectancy), while SDT postulates that behaviour is driven by a need for *autonomy*, *competence*, and *relatedness*. The type of motivation a person has is key to achieving these goals and the theory distinguishes between *intrinsic motivation* and *extrinsic motivation*. Intrinsic motivation includes interest in a subject, desire for self-improvement, ethical values, love, and enjoyment, whereas extrinsic motivation derives from factors such as gaining rewards, the approval of others, and avoiding punishment. If people are motivated by intrinsic motivation, they are more likely to feel autonomy, competence and relatedness and achieve psychological wellbeing. It has been hypothesised that peer mentoring can help to enhance intrinsic motivation by focusing on nurturing an individual's interests and values.

Transformative learning theory is a theory of adult learning and education put forward by Mezirow (Mezirow, 2008). The theory states that transformative learning is "the process of effecting change in a *frame of reference*" (Mezirow, 1997, p.5). These frames of reference are the set of assumptions by which people understand the world and their experiences. After a major life event, such as a life changing injury, these assumptions are challenged, and the way people think about themselves and their lives changes. These changes can be positive or negative, and the way an individual changes their frame of reference is vital to adapting to a new situation. Transformative learners "move

toward a frame of reference that is more inclusive, discriminating, self-reflective, and integrative of experience" (Mezirow, 1997). Some of the studies discussed in the following section investigated whether peer mentoring encourages transformative learning by helping people to accept the person they are after injury and develop a new identity, rather than focusing on the person they were before.

1.9.1 Summary of Sections 1.8 and 1.9

Peer mentoring is an increasingly popular means of helping people with disabilities to feel engaged and connected (Goldman et al., 2013; Rini et al., 2006). It is a growing field, with some theoretical foundations which have been briefly introduced. The following sections provide a detailed introduction to the evidence supporting the development of an intervention for this project. The findings build on some of the theory and ideas introduced above and will provide an initial foundation to the key ideas of the project.

1.10 Peer Mentoring Research Evidence

This section begins with a brief outline of ABI peer mentoring, which will be developed in Chapter Two's systematic review, before discussing the evidence from spinal injuries research.

1.10.1 ABI Peer Mentoring

Several studies have investigated peer mentoring for people with ABI, and these are the subject of the systematic review in Chapter Two. The review included only published papers, so conference abstracts were not included; however, eighteen conference abstracts describing peer mentoring projects for ABI were identified by the literature search and it is informative to provide a

brief overview of these here. The abstracts provided limited information, but did report evidence of participant satisfaction (Boschen, 2012; Gargaro and Boschen, 2012; Balfanz-Vertiz and Taylor, 2010; Beaver et al., 2012; McKellar et al., 2014; Rashid, 2012); improvements in mood and confidence (Boschen, 2012; Gargaro and Boschen, 2012); community integration (Elton-Smith and Palashniuk, 2013; Boschen, 2012; Gargaro and Boschen, 2012; Rashid, 2012); depression, empowerment, life-satisfaction, coping and communication with healthcare professionals (Hibbard and Cantor, 2005); engagement with cognitive rehabilitation (Kingsley and Cicero, 2009); and feasibility in inpatient settings (Elton-Smith and Palashniuk, 2013; Beaver et al., 2012; Collins et al., 2015; McKellar et al., 2014; McKellar et al., 2012; Rashid, 2012; Thomas et al., 2015), and community settings (Boschen, 2012; Gargaro and Boschen, 2012; Hibbard and Cantor, 2005). Most of the projects took place in Canada or the USA. Published papers were produced from one of the studies (Strucheon et al., 2010), but it is unclear why the others never proceeded to larger studies or were published in full.

1.10.2 Spinal Cord Injury Peer Mentoring

Peer mentoring has been studied more extensively as rehabilitation for spinal cord injury (SCI) than it has for any other form of illness or disability. SCI has similarities to brain injury in that it is a life-changing neurological condition which limits physical function, impairs independence, causes depressive disorders, and requires significant readjustment and adaptation (Nas et al., 2015). Although there are also many differences between the effects of ABI and SCI (most obviously the cognitive impairments and personality changes caused by brain injury) the variety, detail, theoretical grounding and

methodological rigour of the research into peer mentoring for SCI can teach us a lot about the benefits of peer mentoring, how it should be designed, and the challenges to implementation.

At the highest level of evidence, there have been two randomised controlled trials (RCTs) into peer mentoring for SCI and I report the quality of these using the Modified Jadad Scale (Han et al., 2019). Both of these RCTs examined the impact of mentoring on self-efficacy from a standpoint of Bandura's self-efficacy theory of social learning (Bandura, 1977). An RCT of a telephone mentoring intervention called 'My Care My Call' (MCMC) compared 42 participants receiving MCMC to 42 controls (Houlihan et al., 2017). This was a high-quality trial, scoring 7/8 on the Jadad Scale assessment. The intervention involved experienced mentors (>five years post-injury) helping mentees (>one year post-injury) to manage medical complications by using skill development, motivation, information, resources, goal setting, and support-network building. Intervention participants showed significantly greater changes on the Patient Activation Measure (PAM) than controls, indicating improved knowledge, skills, and confidence with managing their own health. They also had significantly greater decreases in social role/activity limitations, higher levels of life satisfaction, better awareness of services/resources, more overall service use, and more services used.

The other RCT investigated the effect of peer mentoring on enhancing self-efficacy and reducing hospital readmissions after discharge from an SCI inpatient rehabilitation hospital (Gassaway et al., 2017). This was another high-quality RCT, scoring 6/8 on the Modified Jadad Scale. Participants were randomly assigned to the peer mentoring intervention group (n = 77) or a

control condition to receive traditional peer support services (n = 81). The intervention participants were introduced to a peer mentor and met them weekly throughout the inpatient stay and for 90 days post-discharge. Follow-up assessments occurred at 3-, 30-, 90-, and 180-days post-discharge. The mentoring group showed greater improvements in self-efficacy during the first six months on the General Self-Efficacy Scale (GSE), and fewer hospital readmissions, than the control group. However, there was considerable variation within and between groups at each follow-up time-point and the implications of the findings are unclear.

Quasi-experimental studies represent the next level of evidence quality after RCTs. From this category, an interrupted time-series study evaluated the combined effect of peer mentoring and peer-led patient self-management education classes on hospital readmissions and self-efficacy (Jones et al., 2019). The hypothesis was that the interventions would support transformative learning, therefore leading to greater self-efficacy. Using interrupted time series (ITS), analysis the researchers examined the effects of the two interventions across 24 months pre-implementation as standard practice in an Atlanta hospital, and 24 months post-implementation. Mentors met with their partners in-person or by telephone weekly during the inpatient stay and up to 90 days post-discharge. The peer-led education programme involved four one-hour classes focusing on self-management of SCI-related issues, such as skin care and bladder and bowel management. There were significant decreases in the number of patients readmitted and the number of days they were re-hospitalised following implementation of the mentoring and education programmes. Quasi-Poisson regressions showed a significant effect for the

relationship between peer mentoring and the number of days re-hospitalised, and a near significant effect for peer mentoring on the number of patients with readmissions. No such effects were observed for the peer education classes. Furthermore, high exposure to the peer mentoring intervention was associated with greater self-efficacy and fewer days of re-hospitalisation. These results suggest that peer mentoring helped participants to improve self-efficacy and reduce the number and length of readmissions, and that mentoring was more effective than the education classes. However, there is no evidence that transformative learning was the mechanism for these changes.

Another quasi-experimental study was a static group comparison, which examined the differences between adult mentees and non-mentees on QOL and participation (Sweet et al., 2018). The hypothesis was that self-determination theory's concepts of autonomy, competence and relatedness are mediators of peer mentorship and QOL/participation. A total of 68 mentees (people who had received at least four mentoring sessions in the previous five years) and 63 non-mentees (no previous mentoring interactions) participated. All had sustained an SCI at least one year previously. QOL was assessed on the Life Satisfaction-11 Scale (Fugl-Meyer et al., 1991) and Positive and Negative Affect Schedule (PANAS) (Watson et al., 1988); participation was measured on the Patient-Perceived Participation in Daily Activities Questionnaire (Noreau et al., 2013); and autonomy, competence, and relatedness were measured with the Balanced Measure of Psychological Needs Scale (Sheldon and Hilpert, 2012). There were no differences between the groups for QOL or participation. However, mentees reported slightly greater competence and relatedness than non-mentees. Competence and relatedness were also found to

be significant mediators in the relationship between mentoring and QOL/participation, suggesting that mentoring enhances competence and relatedness, which in turn helps to increase QOL and participation.

Several non-controlled pre-test/post-test studies have provided a lower level of quantitative evidence. A feasibility study at two Danish rehabilitation centres found it was feasible to operate a nationwide volunteer peer mentoring service for SCI inpatients with a high degree of control and stringency (Hoffmann et al., 2019). The study ran for one year and found that QOL, assessed with the International SCI QOL Basic Data Set (Charlifue et al., 2012) improved significantly after the intervention. The results showed that 94% of 52 mentees said they would recommend peer mentoring to other SCI survivors. A 2011 study assessed 28 young men with violently acquired SCI who were helped by peer mentors at a rehabilitation unit (Balcazar et al., 2011). The mentors talked to the patients about issues such as health, housing, and education. Patients were administered the Craig Handicap Assessment and Reporting Technique (CHART) questionnaire at intake and discharge (approximately 12 months apart) to assess activities of daily living, independence, cognition, occupational performance, and social integration. Wilcoxon signed-rank tests showed significant improvements on the cognitive ability and occupation sub-scales of the CHART.

A similar study used peer mentors to help 37 inpatients at a United States rehabilitation hospital with the prevention of secondary conditions and general health maintenance by sharing knowledge, demonstrating skills, and referring to rehabilitation professionals (Ljungberg et al., 2011). Partnerships lasted one year, with meetings (either in hospital or by telephone) occurring weekly for

three months, fortnightly for the next three months and monthly for the final six months. Self-efficacy, medical complications, and opinions on the programme were assessed with the General Self-Efficacy Scale (GSE), mentor report forms and qualitative interviews. Nonparametric tests showed that at six months, 67% of mentees had an increased self-efficacy score, although the results were not statistically significant. Rates of secondary medical complications and doctor visits decreased significantly between six months and 12 months. All mentees were satisfied with their mentor, rated the programme highly, reported the psychological benefits of sharing concerns and said they gained knowledge of their condition.

Qualitative studies have shown the main benefits of SCI peer mentoring to be 'psychological and emotional support from a person with SCI'; 'understanding and empathy'; 'advice on living with SCI'; 'practical advice and information'; 'role modelling'; and 'ongoing support and friendship' (Haas et al., 2013). Peer mentors have been shown to employ transformational leadership theory's constructs of *inspirational motivation*, *idealised influence*, *individualised consideration*, and *intellectual stimulation* through encouragement, promoting achievement, demonstrating optimism and enthusiasm, setting high expectations, role modelling, fostering trust and respect, empathy, understanding, responsive and caring behaviour, recognising individual needs, changing perspectives, and reframing problems (Beauchamp et al., 2016). These behaviours enhanced mentees' motivation and self-confidence, which helped them to redefine limitations, find greater hope, overall well-being, comfort, acceptance, and engagement in social and leisure activities. Furthermore, the mentors displayed the behaviours without having any

transformational leadership training. Qualitative interviews with twelve peer mentors also found that they inherently used transformational leadership behaviours (Shaw et al., 2018).

From the perspective of self-determination theory, qualitative research has shown mentoring to enhance mentees' autonomy, competence and relatedness (Chemtob et al., 2018). Semi-structured interviews with 13 SCI mentees revealed that participants found autonomy by having personalised sessions and being able to make their own decisions. Mentors facilitated competence by providing encouragement, positive feedback, and helping mentees to complete tasks successfully. The mentors displayed caring and empathy which helped the mentees to connect with them and feel relatedness. Mentees were thwarted in achieving these needs when mentors did not listen to them or acknowledge their feelings. Interviews with mentees in a hospital-based peer mentoring service have emphasised the mentors practical, emotional and identity-changing influence, and showed that there are five main components which make mentoring different to other supportive relationships: credibility, equitability, mutuality, acceptance, and normalisation (Veith et al., 2006). Post-intervention qualitative interviews showed that mentors and mentees found mentoring to be a positive experience (Balcazar et al., 2011).

Important considerations when designing a mentoring service are the characteristics of good peer mentors, matching criteria for pairs, and outcomes. Delphi methodology has been used to identify 225 important mentor characteristics categorised into six overarching themes: 1) competencies (e.g., good listener); 2) personality characteristics (e.g., caring); 3) emotional state (e.g., calm); 4) outlook (e.g., positive); 5) reason for mentoring (e.g., desire to

make a difference); and 6) being a role model (e.g., inspiring) (Gainforth et al., 2019). There were five matching criteria for a hospital setting: 1) language; 2) understanding each other; 3) availability; 4) disability level; and 5) experience with similar challenges. Six matching criteria were identified for a community setting: 1) mentor's knowledge matches mentee's needs; 2) time availability; 3) outlook and approach; 4) knowledge about community-based resources; 5) similar lifestyle goals that the mentee wants to achieve/experience; and 6) experience with similar challenges. Most criteria related primarily to the lifestyle, interests, and experience of the mentor rather than demographic factors such as age or gender.

A recent systematic review identified the most important outcomes of SCI peer mentoring for mentees (Rocchi et al., 2021). The study identified 21 qualitative studies published in peer-reviewed academic journals and 66 community documents (e.g., web pages, newsletters, etc.). A total of 87 outcomes of peer mentoring were identified, which were categorised into the following six higher order themes, with 18 sub-themes: 1) adaptation (sub-themes: adapting practice; skills); 2) connection (general support; with others; with those who understand); 3) growth (future feelings and emotions; identity; motivation; outlook and adjustment; present feelings and emotions; wellbeing); 4) independence (independence; demonstration of independence; capability); 5) knowledge (opportunities and resources; new information); and 6) participation (health and recreational activities; community involvement).

1.10.3 Summary of Section 1.10

The literature on ABI and SCI peer mentoring has provided significant qualitative evidence for the psychological benefits and enjoyment peer

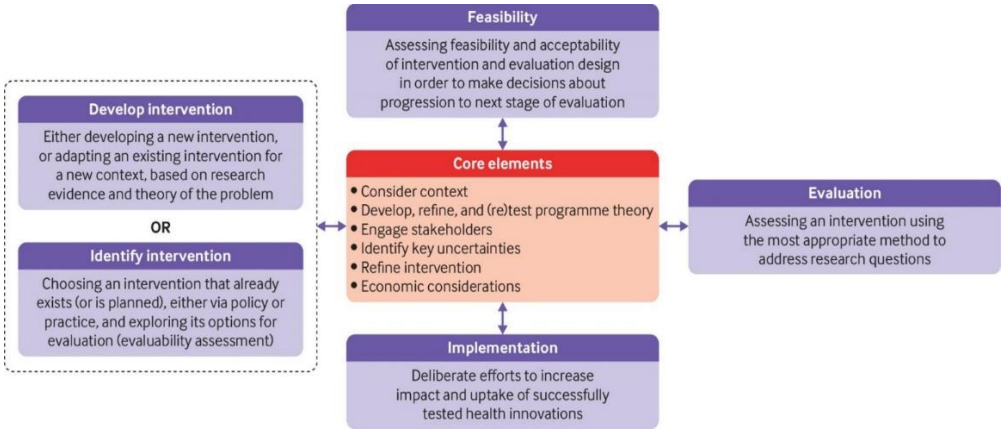
mentoring provides. There is valuable information about key outcomes, mentor characteristics, and matching criteria which can be applied to brain injury peer mentoring research. There is also support for theoretical frameworks which can help us to understand the mechanisms by which mentoring can influence behaviour change. However, despite the robust methodological quality of the RCTs, they showed little evidence for quantitative improvements on standardised instruments.

The following chapter will present a full systematic review of ABI peer mentoring, which will add to the evidence presented above. The next section of this chapter will present how this and the rest of the study will be used to develop a peer mentoring intervention for ABI which can be trialled later.

1.11 Developing a Peer Mentoring Intervention

This study will address the gaps in knowledge by developing and piloting a peer mentoring intervention informed by the Medical Research Council's guidance for developing and evaluating complex interventions (Skivington et al., 2021). The MRC framework sets out four main phases of intervention research, which are essential to understanding how an intervention will work in a real-world environment and to identifying potential barriers. These phases are the following: Develop or identify intervention; Feasibility; Evaluation; and Implementation. Within these phases there are six core elements: Consider context; Develop, refine and (re)test programme theory; Engage stakeholders; Identify key uncertainties; Refine intervention; and Economic considerations.

Figure 1.1. MRC Framework.



Note: Figure reproduced with kind permission of the authors.

The MRC framework emphasises the need to develop interventions with a systematic and evidence-based approach and to use pilot testing. The aim is to increase the likelihood that interventions will work when applied in clinical practice. The involvement of service users is integral throughout the process and qualitative research methods, such as interviews and focus groups, are useful for finding out their views, analysing feedback and incorporating them into the design.

The findings presented in this chapter demonstrate that peer mentoring interventions can take many forms, be implemented in numerous ways, and there is no definitive, evidence-based design to be used. Furthermore, it is vital to consider the context in which the intervention will be delivered (Wade, 2020; Wade and Halligan, 2003) and the expectations, needs, and wishes of the people who will actually be using the service being developed. The previous studies presented in this chapter and Chapter Two were all conducted in very different contexts to the one in which this study will operate. Most were in different countries, with different health/social care systems, different socio-cultural milieu, different service user demographic features, user expectations,

and, crucially, resource availability. Therefore, in order to develop an intervention catering for the needs of the target client group, and which can be implemented in the desired context, I will engage with stakeholders, elicit their feedback and analyse the results. In so doing, I will incorporate theoretical frameworks using the ICF, the behaviour change wheel (BCW) (Michie et al., 2011; Michie et al., 2014), and the Template for Intervention Description and Replication (TIDieR) (Campbell et al., 2018; Hoffmann et al., 2014). These frameworks will inform the data collection and analysis of the engagement work presented in Chapter Three.

2 Chapter Two: Systematic Review

2.1 Chapter Summary

The first stage of developing an intervention is to identify and evaluate the existing evidence for ABI peer mentoring. Therefore, I conducted a systematic review, which is described in this chapter. The chapter will begin with an introduction and rationale for the review, followed by an outline of the aims and objectives. I will then describe the methods, including the inclusion and exclusion criteria, search strategy, data extraction methods, and analysis methods. I will then present the results of the search and an overview of the studies identified, before presenting the important findings from the studies and their implications for this project.

2.2 Introduction

The introductory chapter has presented a view of the physiology of brain injury and its impact on individuals and society. A case has been made for the importance of rehabilitation tailored to the individual and the need to explore ways of helping people to live fulfilling lives. I have shown that peer mentoring is an innovative and promising approach, which has a sizeable body of evidence from spinal injury research and has attracted growing interest for ABI. I have presented an outline of the three studies which this PhD will use to design a peer mentoring intervention and test the feasibility of its delivery. This chapter presents the first of those three studies, which was a systematic review of the current evidence regarding peer mentoring after ABI.

2.3 Rationale

Peer mentoring fits the Medical Research Council's (MRC's) definition of a complex intervention, i.e., one containing several interacting components; several complex behaviours required by those delivering and receiving; targeting several groups or organisational levels; having multiple outcomes of a variable nature; and having a degree of flexibility or tailoring (Skivington et al., 2021). The MRC guidelines recommend that when developing a complex intervention, it is first necessary to identify the relevant existing evidence base, ideally by conducting a systematic review. Systematic reviews are at the top of the evidence hierarchy for healthcare interventions, along with multi-centre studies and above randomised controlled trials (Evans, 2003). This hierarchy is important in that it encompasses three dimensions: effectiveness, appropriateness, and feasibility. Some systematic reviews focus entirely on the effectiveness of an intervention, including Cochrane reviews which are rated as the highest standard of review and usually include only randomised controlled trials (RCTs), as these provide the highest quality evidence of effectiveness. However, when assessing complex interventions in a feasibility study such as this one, it is important to review all evidence from previous studies in the field and assess what is known about effectiveness, study design, appropriateness, acceptability, recruitment methods, eligibility criteria, training, resource requirements, participant satisfaction, etc. The most appropriate way to do this was to include studies of any methodology, rather than solely focus on RCTs.

A previous systematic review by this author looked at peer mentoring for traumatic brain injury (TBI) rather than other forms of ABI such as stroke (Morris et al., 2017). The review included six studies, including two RCTs, all

of low quality, which found no significant improvements in social activity level or social network size, but some significant improvements in areas including behavioural control, mood, coping, and quality of life. The purpose of that review was for a project focussing on TBI survivors, which necessitated the narrow scope regarding the participant group. However, the literature searches identified some studies of interest with participants who had other forms of ABI (Coles and Snow, 2011; Fraas and Bellerose, 2010). Therefore, for the purposes of this study, it was necessary to expand the scope of the previous review to encompass all forms of acquired brain injury and to update it to include any recently published studies.

2.4 Review Aims and Objectives

The review sought to answer three main questions to inform the design of the intervention:

1. What has previous research told us about the design and implementation of a peer mentoring intervention for brain injury survivors?
2. What is the evidence for peer mentoring's effectiveness for enhancing participation in activities among people with acquired brain injuries?
3. What other outcomes have been studied and what is the evidence of peer mentoring's effectiveness for them, primarily for mentees but also for mentors?

2.5 Review Methods

This review was carried out in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et

al., 2009) (see Appendix 1). A protocol was registered on the PROSPERO International Prospective Register of Systematic Reviews (CRD42016050395).

2.5.1 Types of Studies

Studies of any design which employed a model of individualised peer mentoring between ABI survivors of any age were included. The term 'peer mentoring' is used here for consistency, but similar concepts may be defined differently and use a variety of models. Any form of peer mentoring intervention which did not vary widely from the model of individualised peer support was included in the review. Only papers published in English in peer reviewed journals and providing a full account of the study were included. Conference abstracts, grey literature, opinion pieces, systematic reviews, and book chapters were excluded. The review was restricted to peer reviewed published research to ensure rigour and enable quality appraisal and comparison of methods and results. I was aware that doing so would potentially omit abstracts and posters, such as those referenced in Section 1.10.1, or book chapters, reports, pamphlets, bulletins, newsletters, protocols of unpublished studies, trial data, and theses. However, it was important to gain enough information about methodology and results to be able to make informed conclusions about the quality and value of the information gained. There was insufficient detail in the published abstracts regarding methods, participants, and results, so it would be inappropriate to include them in a systematic review. Such items were used to inform my understanding of the topic and are discussed in the thesis where appropriate (e.g. in Section 1.10.1).

A PICO-S (Population; Intervention; Comparator; Outcomes; Study design) screening and selection tool was used to assess studies for eligibility, as shown in Figure 2.1:

Figure 2.1. PICO-S screening and selection tool.

SCREENING AND SELECTION TOOL			
Reviewer name:			
Author name/study ID:			
Source/Journal			
	Include	**Exclude**	**Unclear**
Patient population:	☐ Acquired brain injury	☐ Any other health condition or no-disability	☐
Intervention:	☐ ABI survivors acting as mentors to other ABI survivors (described in full above).	☐ non-peer mentoring (e.g., group support or any other form of intervention)	☐
Comparators	☐ Any	☐ NA	☐
Outcomes of interest:	☐ Any	☐ NA	☐
Study:	☐ Any design ☐ Full study published in peer reviewed journal	☐ Conference poster/abstract ☐ Opinion piece	☐
Language:	☐ English	☐ not published in English	☐
Overall decision:	☐ INCLUDED	☐ EXCLUDED	☐ NEED MORE INFO/FULL TEXT
Further comments:			

The five elements of the PICOS selection criteria were defined as follows:

Population: People with long-term cognitive, physical, emotional, and/or behavioural deficits as a result of acquired brain injury (ABI); i.e., any non-degenerative, non-congenital injury to the brain acquired since birth.

Intervention: One-to-one support from one brain injury survivor to another. Any form of group support should be excluded.

Comparator: None**.**

Outcomes: The following outcomes were selected for data extraction, but studies were not excluded on the basis of their outcomes. Primary: Measures of activities, participation, social interaction and community integration. Secondary: Measures of mood; disability management; behaviour management; confidence; resilience; adverse events; any other measures employed.

Study design: Any study design. Full study published in peer-reviewed journal.

2.5.2 Search Strategy

Search strategies were developed across a range of databases using indexing terms (e.g., medical subject headings (MeSH) and Embase's Emtree thesaurus) and text words relating to acquired brain injury and peer mentoring. The search strategy, including wildcards and truncations, was adapted to the requirements of each database (see Appendix 2 for an example).

The following twelve medical, health, social care, and psychology databases were searched in late October/early November 2016:

MEDLINE (Ovid: 1946 to 28.10.16); MEDLINE In-Process & Other Non-Indexed Citations (Ovid; 28.10.16); PsycINFO (Ovid: 1806 to Week 3 2016); EMBASE (Ovid: 1974 to 27.10.16); CINAHL Plus with Full Text (EBSCOHost: 1986 to 29.10.16); Web of Science Core Collection (Thomson Reuters: 1970 to 29.10.16); Scopus (Elsevier: 1970 to 29.10.16); Cochrane Library (including Cochrane Database of Systematic Reviews (CDSR); Cochrane Central Register of Controlled Trials (CENTRAL); Cochrane Methodology Register (CMR); Database of Abstracts of Reviews of Effects (DARE); Health Technology Assessment Database (HTA); NHS Economic Evaluation Database (EED) (Wiley: 1996 to 29.10.16); AMED (Ovid: 1985 to 28.10.16); ASSIA: Applied Social Sciences Index and Abstracts (ProQuest: 1987 to 31.10.16); Joanna Briggs Institute EBP database (Ovid: 1998 to 26.10.16); and LILACS (Bireme 1982 to 1.11.16).

Hand searches of reference lists of relevant papers were conducted, and citation searches were undertaken using the SCOPUS and Google Scholar citation search facilities. I imported all citations from each database into EndNote X7.7, removed duplicates, added additional records from other sources and sent the final library to a second researcher (JFS). We independently assessed all titles and abstracts using the PICO-S screening and selection tool, shortlisted studies for inclusion, and discussed any discrepancies. We were not blinded to journal titles, authors, or institutions. Full texts were obtained for all shortlisted articles, and we independently assessed them for inclusion in the review. We independently compared our selections and discussed any further discrepancies, while any remaining disagreements were resolved through

consultation with my chief supervisor, KR. The reasons for excluding studies were recorded.

The search was updated to find any newly published studies in October 2022. The results of this search are outlined in Section 2.8, where newly published studies are briefly described. An example of the updated search results for one database are presented in Appendix 2.

2.5.3 Data Extraction

The two researchers (RM and JFS) conducted the data extraction independently before comparing results and removing any discrepancies through discussion. Data were extracted on the following elements: participant details; intervention design; details of mentor training; logistical challenges; outcomes and results; and study methodology. The elements of the intervention design were extracted using a data extraction tool informed by the Template for Intervention Description and Replication (TIDieR) checklist (Hoffmann et al., 2014). Results will be reported with reference to the items on the checklist: Why; What; Who provided; How; Where; When and how much; Tailoring; Modification; How well (see Appendix 3 for full TIDieR checklist). Tables listing the TIDieR checklist data for each study are in Appendix 4.

2.5.4 Analysis

A narrative synthesis of the data was undertaken in accordance with published guidelines (Popay et al., 2006). This narrative synthesis focused on elements of the design, implementation, and effectiveness of the interventions.

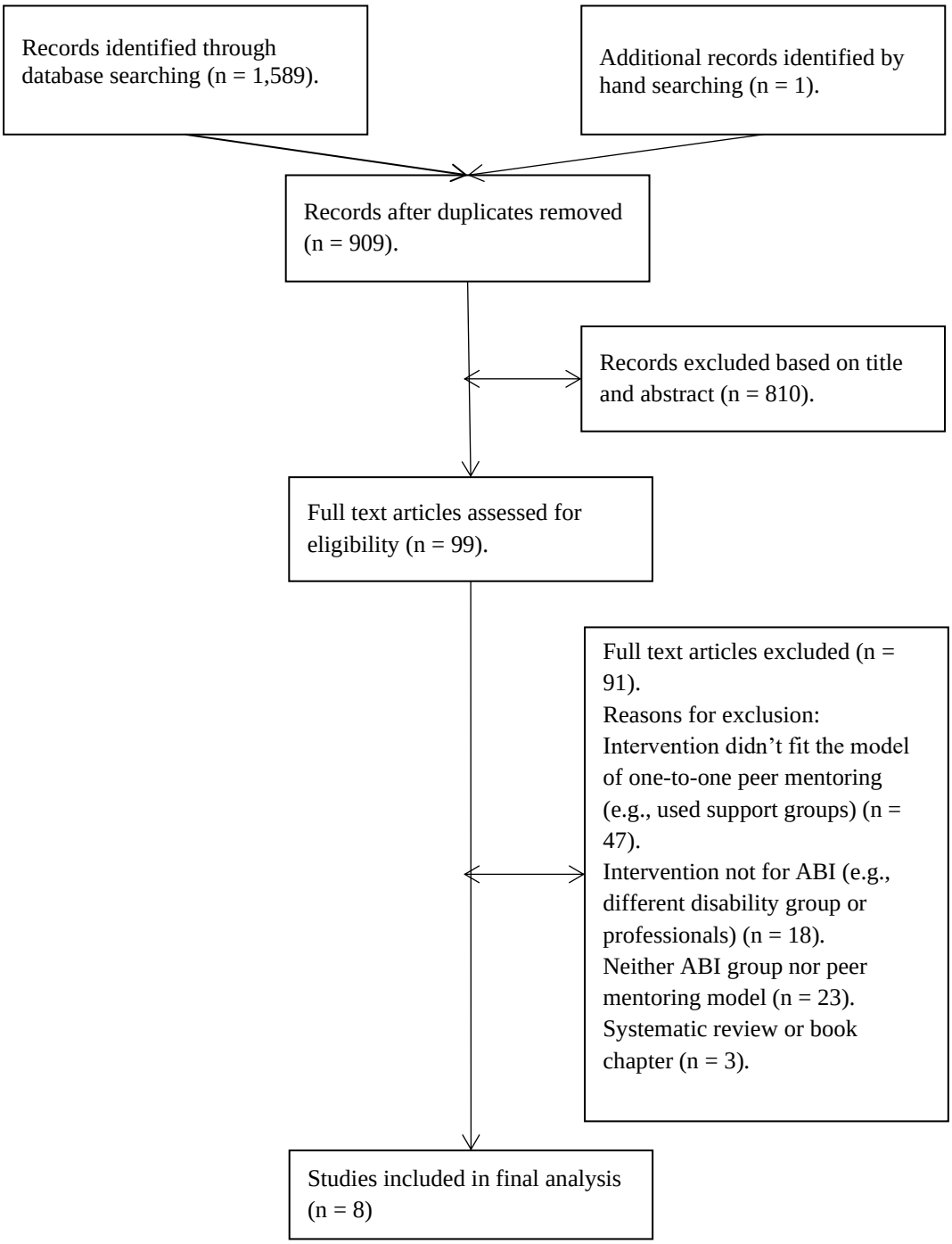
2.6 Results

This section presents the results of the literature search and a synthesis of the results from the included studies.

2.6.1 Search Results

The database search returned 1,589 records with one further study identified through hand searching of reference lists. No further studies were identified through citation searches of authors. After duplicates were removed, 909 records remained, and 810 of these were excluded after screening. Full texts were obtained for the remaining 99 records and 91 were excluded, leaving a total of eight studies for inclusion. Figure 2.2 shows the flow diagram of the selection process.

Figure 2.2. Flow diagram of systematic review selection process.



2.6.2 Summary of Study Designs and Quality Assessment

The studies included two randomised controlled trials, two service descriptions, two case studies, one concurrent mixed methods design with no control group, and one quantitative before-and-after study with no control

group. Table 2.1 lists each study with a description of the design and country of origin.

Table 2.1. Included studies and summary of designs.

Study reference	Country	Summary of design
Applying the Principles of Peer Mentorship in Persons with Aphasia (Coles and Snow, 2011).	USA	Descriptions of services.
A Model System of Traumatic Brain Injury Peer Support Importance, Development and Process (Moreci, 1996).	USA	
Mentoring Programme for Adolescent Survivors of Acquired Brain Injury (Fraas and Bellerose, 2010).	USA	Case study of single paring. Quantitative measures and qualitative feedback.
Peer Support in the Community: Initial Findings of a Mentoring Program for Individuals with Traumatic Brain Injury and their Families (Hibbard et al., 2002).	USA	Pilot concurrent mixed methods design. Quantitative and qualitative retrospective evaluations of the TBI Mentoring Partnership (TBI-MPP).
An Effective Community-Based Mentoring Program for Return to Work and School after Brain and Spinal Cord Injury (Kolakowsky-Hayner et al., 2012).	USA	Quantitative before-and-after study with no control group.
Peer Support for Stroke Survivors: A Case Study (Kessler et al., 2014).	Canada	Qualitative instrumental case study evaluation of an individualised peer support programme.
Randomized Controlled Trial of Peer Mentoring for Individuals with Traumatic Brain Injury and their Significant Others (Hanks et al., 2012).	USA	Single-site randomised controlled trials.

Making Connections after Brain Injury: Development and Evaluation of a Social Peer-Mentoring Program for Persons with Traumatic Brain Injury (Struchen et al., 2011).	USA	

Table 2.2 presents the quality assessment results for each study using the Mixed Methods Appraisal Tool (MMAT) (Pluye et al., 2011) for systematic mixed studies reviews.

Table 2.2. MMAT evaluations of included studies.

Item	**Kolakowsky-Hayner**	**Moreci**	**Hibbard**	**Hanks**	**Struchen**	**Coles**	**Fraas**	**Kessler**
Screening Questions								
Are there clear research questions?	Yes	No	Yes	Yes	Yes	No	Yes	Yes
Do the collected data allow to address the research questions?	Yes	No	Yes	Yes	Yes	No	Yes	Yes
Study type	Quan non-randomised	Descriptive	Mixed methods	Quant rand	Quant randomised	Descriptive	Quant non-randomised	Qual instrumental case study
Qualitative								
1.1 Is the qualitative approach appropriate to answer the research question?								Yes
1.2 Are the qualitative data collection methods adequate to address the research question?								Yes
1.3 Are the findings adequately derived from the data?								Yes
1.4 Is the interpretatio								Yes

Item	Kolakowsky-Hayner	Moreci	Hibbard	Hanks	Struchen	Coles	Fraas	Kessler
n of results sufficiently substantiated by data?								
1.5 Is there coherence between qualitative data sources, collection, analysis and interpretation?								Yes
Quantitative Randomised Controlled Trials								
2.1 Is randomization appropriately performed?				Can't tell	Can't tell			
2.2 Are the groups comparable at baseline?				Yes	Yes			
2.3 Are there complete outcome data?				Yes	Yes			
2.4 Are outcome assessors blinded to the intervention provided?				Yes	Can't tell			
2.5 Did the participants adhere to the assigned intervention?				No	No			
Quantitative Non-Randomised								
3.1 Are the participants representative of the target population?	Yes						Yes	
3.2 Are measurements appropriate regarding both the outcome and intervention (or exposure)?	Yes						Yes	

Item	Kolakowsky-Hayner	Moreci	Hibbard	Hanks	Struchen	Coles	Fraas	Kessler
3.3 Are there complete outcome data?	Yes						Yes	
3.4 Are the confounders accounted for in the design and analysis?	No						No	
3.5 During the study period, is the intervention administered (or exposure occurred) as intended?	No						Yes	
Mixed Methods								
5.1 Is there an adequate rationale for using a mixed methods design to address the research question?			Yes					
5.2 Are the different components of the study effectively integrated to answer the research question?			No					
5.3 Are the outputs of the integration of qualitative and quantitative components adequately interpreted?			No					
5.4 Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?			No					
5.5 Do the different			No					

Item	Kolakowsky-Hayner	Moreci	Hibbard	Hanks	Struchen	Coles	Fraas	Kessler
components of the study adhere to the quality criteria of each tradition of the methods involved?								

Although the MMAT does not allow for the scoring of studies to rate quality, we can see that most of the studies were of low evidence quality and high risk of bias. The instrumental case study by Kessler was an exception to this, being a methodologically high-standard qualitative study. A specialised RCT assessment tool is better suited to assessing the quality of the RCTs, so Table 2.3 presents an assessment using the Modified Jadad Scale (Jadad et al., 1996).

Table 2.3. Modified Jadad Scale assessments of systematic review RCTs.

Item	Hanks	Struchen
Was the study described as randomised?	Yes +1	Yes +1
Was the method of randomisation appropriate?	No -1	Not described 0
Was the study described as blinding?	Yes +1	No 0
Was the method of blinding appropriate?	Not described 0	Not described 0
Was there a description of withdrawals and dropouts?	No 0	Yes +1
Was there a clear description of the inclusion/exclusion criteria?	Yes +1	Yes +1
Was the method used to assess adverse effects described?	No 0	No 0
Was the method of statistical analysis described?	Yes +1	Yes +1
Total score	3	4

The assessment shows that the RCTs were poorly conducted or reported in several elements, although double blinding is not possible in a peer mentoring study so full marks would be unattainable.

The overall standard of the quantitative evidence available from this systematic review is poor and there can be no clear conclusions regarding the effectiveness of peer mentoring. It is also not possible to conduct a meta-analysis due to the different methodologies and outcome measures used.

2.6.3 Data Extracted from Studies

The narrative synthesis presents and compares information from the studies based on the elements of participants, intervention design (mapped to the TIDieR elements), outcomes, and results.

Populations

There were differences between the studies in the precise nature of the populations under investigation:

- Adult stroke survivors with aphasia (mentors and mentees): Coles and Snow, 2011.
- Adult traumatic brain injury (TBI) survivors (mentors and mentees): Moreci, 1996; Struchen et al., 2011.
- Adolescent with encephalitis (mentee) and TBI (mentor): Fraas and Bellerose, 2010.
- Adults with TBI and family members (mentors and mentees): Hibbard et al., 2002.
- 16–26-year-olds with neurological conditions (including TBI) (mentees); adults with neurological conditions, rehabilitation

professionals or family members (mentors): Kolakowsky-Hayner et al., 2012.

- Adult stroke survivors (mentors and mentees), plus health professionals, programme co-ordinators and care partners (for qualitative evaluation): Kessler et al., 2014.
- Adults (16 years old and over) with TBI and significant others (mentors and mentees): Hanks et al., 2012.

Participant Numbers and Demographic Characteristics

One service description paper reported delivering support to 200 TBI survivors with 22 peer supporters from 1994 to 1996. The other service description reported four mentors delivering support to 19 stroke survivors. The mentor in the case report section of Coles and Snow was a 67-year-old male, three years post-stroke and the mentee was a 33-year-old female, two years post-stroke. The case study of Fraas and Bellerose reported a 26-year-old male with TBI mentoring a 14-year-old male encephalitis survivor. It was not reported precisely how long after injury the two participants in the case study were.

Hibbard et al. provided the results of interviews with 20 mentees, including 11 TBI survivors and nine family members. Demographics were provided for the group as a whole and did not differentiate between TBI survivors and family members, with the majority being female (n = 14), white (n = 14), and 31 years old or over (n = 18). No details were provided about the mentors of study participants, although demographics were reported for the 114 mentors in the overall programme, 70% of whom were TBI survivors and the rest family members. It was not specified how long after injury the TBI mentors were.

Kolakowsky-Hayner et al. included 121 trained mentors in the programme, with 58% male and 29% with TBI (the rest had other forms of neurological disabilities or no disability). There were 131 mentees in the programme (which was not time limited but had a two-year cut off point for assessment purposes), with demographics and results provided for the 89 who completed the partnership. These were 69% male and 64% had TBI. Mentors were a minimum of two years post-injury and mentees were an average of 503 days post-injury.

Kessler et al. report 13 peer supporters in their programme, of which seven participated in the study. There were baseline interviews with 16 stroke survivors who received support, and 14 completed follow-up interviews at one, three, six, nine and twelve months. The mean age was 64.8 and the majority (75%) were male. It was not reported how long ago the peer supporters sustained their strokes, while those receiving support were in the early stages of recovery on an acute ward.

Of the two randomised controlled trials only Struchen et al. reported demographic details of mentors. The 11 mentors had a mean age of 36.3 years and the majority (64%) were male, white (82%), and had severe brain injuries (73%). The same study reported demographics for the mentored and control groups combined (n = 30). The mean age was 31.7 years, while the majority were male (80%), and had a severe injury (73%), 47% were white, 23% black, and 27% Hispanic. The 47 mentored TBI participants in the Hanks et al. study had a mean age of 38.46 years, were predominantly male (89%) and black (72%). A breakdown of injury severity was not provided but the average Glasgow Coma Score (GCS) was 9.39, indicating a majority of moderate

injuries. The GCS range for both mentored and control groups was 3–15, showing the broadest possible range of injury severities. The TBI control group showed a similar demographic profile to the mentored group. There was a broad range of ages among both groups (17–86). The mentors in the Struchen et al. study were a median of 6.2 years post-injury, while the mentees were a median of 1.6 years post-injury. Mentors in the Hanks study were at least two years after injury, while mentees were all in the early stages after discharge from hospital.

Mentor Eligibility Criteria and Desirable Characteristics (Who)

There was some overlap between the studies in the criteria they specified for mentors:

- Good listener: Coles and Snow; Moreci; Hibbard et al.; Fraas and Bellerose
- Empathy: Coles and Snow; Moreci; Hibbard et al.; Fraas and Bellerose
- Shares life experiences: Coles and Snow; Moreci
- Willingness and motivation to help others: Hibbard et al.; Fraas and Bellerose; Hanks et al.
- Good personal adjustment, social competency, and lack of behavioural problems: Hibbard et al.; Fraas and Bellerose; Kolakowsky-Hayner et al.; Struchen et al.; Hanks et al.

Mentee Inclusion and Exclusion Criteria

Coles and Snow included stroke survivors with aphasia, while those receiving support in the Moreci programme were TBI survivors on a rehabilitation unit. Participants in the Kessler et al. study were stroke survivors on an acute ward.

Fraas and Bellerose's mentee was required to be 13–18 years-old, lack psychiatric or behavioural issues, have insight into personal strengths and limitations, and receive parental consent.

Hibbard et al. specified stringent exclusion criteria, including serious psychiatric or behavioural problems, inability to articulate reasons for wanting support, no personal interest in participating, severe cognitive impairments, and no desire to change their life situation. Kolakowsky-Hayner et al. included 16–26-year-olds with neurological disabilities (including TBI), who had been unable to return to school, work, or their previous level of community participation. Participants in Struchen's study had a medically documented TBI, were 18 years-old or over, community dwelling, and no longer participating in a rehabilitation programme. The TBI participants in Hank's research were at least 16 years old, received acute care at a designated unit within 72 hours of injury, and were directly transferred to a rehabilitation unit.

Mode of Delivery and Setting (How and Where)

Contacts between participants were exclusively face-to-face in the studies of Coles and Snow and Fraas and Bellerose. Struchen et al. intended the primary mode of contact to be face-to-face, although other forms of contact were permitted and most contacts were remote (telephone or email), whereas the primary mode of contact in the Hibbard et al. study was by telephone, with some face-to-face meetings allowed. Moreci and Kessler et al. employed similar models of face-to-face contact for initial visits, then follow-up telephone calls. Hanks et al. allowed face-to-face or telephone meetings, while

Kolakowsky-Hayner et al.'s participants communicated by their preference of face-to-face contacts, telephone, or email.

Initial meetings in the Kessler et al. and Moreci programmes took place in an acute stroke unit and inpatient TBI rehabilitation unit respectively, with follow-up telephone calls to participants' homes. The intervention in the Fraas and Bellerose paper was the only one to take place in the same setting for a series of meetings. This was conducted exclusively at a Community Health and Wellness Facility, which operated group sessions attended by other brain injury survivors. The other studies all allowed contacts in the community at locations of the participants' choosing, after an initial meeting at a hospital or rehabilitation unit in the case of Coles and Snow.

Rationale and Goals (Why)

The studies had the following explicitly stated goals, which outcomes were measured against:

- Improve social integration and participation – Struchen et al.; Hanks et al.
- Community integration – Kolakowsky-Hayner et al.; Hanks et al.
- Enhance self-confidence, self-worth, and communication skills – Coles and Snow
- Provide hope at the acute stage – Moreci: Kessler et al.
- Decrease feelings of isolation at the acute stage – Moreci: Kessler et al.
- Provide information at the acute stage – Moreci: Kessler et al.
- Emotional/cognitive support – Fraas and Bellerose; Hibbard et al.; Hanks et al.

- Help to access community resources, services, and programmes – Hibbard et al.; Kolakowsky-Hayner et al.; Struchen et al.; Hanks et al.
- Enhance quality of life - Fraas and Bellerose; Hanks et al.
- Return to employment or education – Kolakowsky-Hayner et al.
- Knowledge of TBI – Hibbard et al.
- Advocacy skills – Hibbard et al.

Matching of Mentors to Mentees

The two studies which employed peer supporter visits to hospitals or rehabilitation units did not match participants on specific criteria. The other studies all created mentor and mentee partnerships according to specific criteria. The most common criteria shared by the studies were as follows:

- Geographical location (Coles and Snow; Kolakowsky-Hayner et al.; Struchen et al.; Hibbard et al.)
- Gender (Fraas and Bellerose; Hibbard et al.; Kolakowsky-Hayner et al.; Struchen et al.)
- Age (Hibbard et al.; Kolakowsky-Hayner et al.; Struchen et al.)
- Interests (Fraas and Bellerose; Hibbard et al.; Kolakowsky-Hayner et al.; Struchen et al.)

Kolakowsky-Hayner et al. attempted to match for disability type as this was the only study with participants who had different neurological conditions. Unique criteria appeared in the studies of Coles and Snow (current mentee load of mentors; similarity of communication difficulties; and common vision for enhancing quality of life as persons living with aphasia), which had a primary focus on enhancing communication for people with aphasia, and Hibbard et al.

(marital status; educational background; cognitive challenges; physical challenges; cause of traumatic brain injury, e.g., road traffic incident or fall; and ability to meet specific psychological needs, such as the need for structure, a role model, and social support).

Frequency, Intensity, and Duration (When and How Much)

Moreci and Kessler et al. employed similar models, with one visit of up to 30 minutes, followed by a non-specified number of telephone follow-ups (Moreci), and one 10-minute visit followed by six telephone follow-ups of 5–60 minutes (Kessler et al.). There were also similarities between Coles and Snow (one hour, one day per week for eight weeks) and Fraas and Bellerose (one day per week for 10 weeks). Hibbard et al. left the frequency and number of contacts and the duration of the partnership, entirely to the discretion of their participants. Kolakowsky-Hayner et al. specified a minimum of three contacts per month and aimed to end partnerships when mentees had achieved their employment or educational goals, so did not set a specific time limit.

For the two trials, Struchen et al.'s partnerships ran for three months, with a minimum of two meetings per month, while Hanks et al. set the duration of partnerships at 12 months. The pairings were intended to meet weekly for the first month, bi-weekly for the next two to three months, and then monthly for the remainder of the first year. The majority of partnerships in both trials did not meet the requirements for number and frequency of meetings.

Content, Activities, and Processes of Interventions (What: Procedures)

The papers did not describe the precise content of the contacts between pairs. The general structure and purpose of the meetings, mentors' roles, and professional involvement in each study are outlined below.

Table 2.4. Content of interventions and professional involvement.

Study	Content of intervention and professional involvement
Coles and Snow	Mentors modelled communication skills. Offered emotional support. Encouraged mentees to embrace life and increase self-worth. Helped mentees to access community resources and social opportunities. Provided a role model for dependability, honesty, and respect for others. Programme facilitated by three speech and language therapists (SLTs).
Moreci	Peer supporters visited the rehabilitation centre in teams of two, three nights each week for two hours. Provided a listening ear and a sensitive awareness of TBI issues. Were available to discuss brain injury with the family in detail. Made phone calls to offer support to individuals and their families who had left the rehabilitation unit. Programme co-ordinator monitored peer supporters, guided them on the purpose of the visits and structured programme activities.
Fraas and Bellerose	Mentor and adolescent met one day a week from 9:30 am–2:00 pm at a brain injury support centre. From 9:30 until 10:00 the mentor and adolescent got together to catch up and discuss their activities from the past week. Mentor met with the adolescent several times during the day to provide support, have lunch, play board games, and discuss issues of mutual interest, such as sports and leisure activities. Both partners could participate in group activities during the rest of the day. The activities addressed cognitive needs, emotional needs, physical needs, activities of daily living, etc. Researchers facilitated the study using an existing community brain injury support centre programme. Group activities at the centre were facilitated by

	centre staff and volunteers. Programme staff and researchers trained the mentor.
Hibbard et al.	TBI "veterans" were matched with individuals with TBI or family members to provide emotional support, knowledge about TBI and resources, and advocacy skills. Meetings were mainly by telephone, although there were some face-to-face contacts. A project coordinator provided ongoing advice and support to mentors by telephone for the duration of each partnership.
Kolakowsky-Hayner et al.	Mentors encouraged people with neurological disabilities to participate fully in social, academic, and employment-related activities that would improve their quality of life. Completion of the programme was defined as the mentee getting a job or enrolling in post-secondary education. Participants supported by programme co-ordinator, vocational rehabilitation counsellor and rehabilitation psychologist.
Kessler et al.	Visits occurred one day per week. The initial visit was intended to provide a message of hope. The peer supporters conducted their visits working in pairs, these pairs being matched to complement each other's strengths and degree of disability. Follow-up support provided by telephone calls to stroke survivor or care partner at one-, three-, six-, nine- and twelve-months post-discharge. Support and assistance provided by visit co-ordinator, logistics co-ordinator, and programme co-ordinator.
Struchen et al.	Active peer mentoring occurred over a 3-month period. The goal of outings was to increase social networking for the mentee through introductions to people, activities, and resources within their community. Increased social networking could include an increased number of outings, increased number of phone calls and e-mails, and/or an increased number of social visits to the partner's home. Therapist spoke to mentors by phone at least once per week to discuss the relationship. The on-call therapists assisted mentors with problem-solving and met them for booster training sessions when needed.
Hanks et al.	Discussions in mentoring sessions were focused on three main areas: (1) emotional well-being; (2) post-TBI quality of life; and (3) community integration,

	and this was accomplished by the mentors providing social and emotional support, helping the mentee gain access to community resources, and discussion of any topics related to TBI or caregiving that the mentee wanted to discuss. Mentors were hired as contingent employees and involved in weekly in-person supervision from a psychologist, a nurse, and community outreach coordinator. These supervisors were available for 24-hour emergency assistance.

Mentor Training (What: Procedures)

All the studies provided details of mentor training. The following studies described the intensity and regularity of training:

- Moreci – Annual training seminars and on-going bi-monthly informal training meetings.
- Hibbard et al. – Full-day training workshops.
- Kessler et al. – Six hours of in-class group education, a two-hour orientation to the hospital, four-to-six individual sessions shadowing the visit co-ordinator.
- Struchen et al. – Two 2-hour group sessions, supplemented by a written manual and booster training as needed.
- Hanks et al. - Twenty hours of training prior to appointment as mentors. Training consisted of modelling interviewing skills; telephone role playing; discussion of what is and what is not mentoring; communication skills and active listening.

Training was delivered by a variety of professionals including speech and language therapists (Coles and Snow); neuropsychologists (Moreci; Struchen et al.); rehabilitation psychologists (Kolakowsky-Hayner et al.); programme staff,

hospital staff, and researchers (Fraas and Bellerose; Kolakowsky-Hayner et al.; Kessler et al.; Struchen et al.). The training included topics such as communicating to people with aphasia (Coles and Snow); communication and listening skills (Coles and Snow; Moreci; Hibbard et al.; Kessler et al.; Hanks et al.); knowledge of brain injury and effects (Moreci; Fraas and Bellerose; Hibbard et al.; Struchen et al.; Hanks et al.); techniques for building relationships and rapport with mentees (Coles and Snow; Fraas and Bellerose; Hanks et al.); advocacy skills (Hibbard et al.); accessing community resources (Fraas and Bellerose; Hibbard et al.; Struchen et al.); enhancing social functioning and skill acquisition of mentees (Fraas and Bellerose; Hibbard et al.; Struchen et al.); handling difficult situations/inappropriate conversations/problem behaviour (Fraas and Bellerose; Struchen et al.). Some of the programmes provided written guides and training manuals to mentors (Coles and Snow; Hibbard et al.; Struchen et al.; Hanks et al.).

Logistical Problems

Coles and Snow, Moreci, and Fraas and Bellerose did not report any specific logistical problems in delivering their services. The intervention reported by Coles and Snow followed on from formal speech and language therapy, while the programme detailed by Moreci was delivered in a hospital setting. Coles and Snow and Fraas and Bellerose provided a venue for the meetings (at a rehabilitation centre and day centre, respectively).

There was considerable overlap between the other studies in the logistical difficulties they reported. These can be summarised as follows:

- Problems scheduling times and locations for meetings (Kolakowsky-Hayner et al.; Kessler et al.).
- Budgeting for transport (Kolakowsky-Hayner et al.).
- Identifying suitable mentors and matching pairs (Struchen et al.).
- Participant withdrawal (Struchen et al.).
- Providing sufficient staff support time (Kessler et al; Struchen et al.).
- Making allowances for the mentors' cognitive difficulties (Kessler et al.).
- Partners living too far apart (Kolakowsky-Hayner et al.).
- Too many matching criteria (Kolakowsky-Hayner et al.).
- Insufficient duration of service (Struchen et al.).
- Difficulties contacting participants for follow-up (Kessler et al.).
- Loss of participants' interest due to delay between enrolment and matching (Kolakowsky-Hayner et al.).
- Lack of accessible meeting locations (Kolakowsky-Hayner et al.).
- Lack of potential participants' interest in the research aspect of the programmes (Hibbard et al.).
- Difficulty recruiting participants from diverse socio-demographic/ethnic groups and people with minor TBI (Hanks et al.).
- Inability to identify the mechanisms influencing study outcomes (Hanks et al.).

Outcome Measures and Results

The key outcome measures of interest in this review are summarised narratively in Tables 2.5 and 2.6:

Table 2.5. Systematic review primary outcome.

Outcome measures	**Results**
Mayo-Portland Adaptability Inventory (MPAI)-4 Participation domain – Fraas and Bellerose; Kolakowsky-Hayner et al.	Scores for both mentor and mentee in the Fraas and Bellerose study indicated improvement. Programme participants and programme successes in the Kolakowsky-Hayner et al. study showed statistically significant improvements.
Social support section of Traumatic Brain Injury-Mentoring Partnership Programme (TBI-MPP) retrospective questionnaire – Hibbard et al.	82% of participants (n = 11) said that the programme had no impact/not applicable on social support from family members, friends, or the community.
Craig Handicap Assessment and Reporting Technique–Short Form (CHART–SF) Occupation and Social Integration sub-scales – Kolakowsky-Hayner et al.; Struchen et al.	Kolakowsky-Hayner et al.'s participants and programme successes showed improvements on both sub-scales, but these were non-significant. Active peer mentoring participants in the Struchen et al. study showed non-significant improvements on the social integration sub-scale.
Social Activity Interview – Struchen et al.	No improvements in mentored group for number of activities, number of social interactions, or satisfaction with social life since injury. Trend towards increased satisfaction with social life over the past month in the mentored group.
6-item Interpersonal Support Evaluation List (6 ISEL) – Struchen et al.	Significant interaction between time and group status. Mentored group showed an increase in perceived social support while control group decreased.
Weekly Social Activity Survey – Struchen et al.	There were no statistically significant increases in social activity levels.

Community Integration Measure (CIM) – Hanks et al.	The mentored TBI group showed lower scores than the control group. Mentored significant others had significantly lower community integration than controls.

Table 2.6. Systematic review secondary outcomes.

Outcome measures	**Results**
Measures of mood: Centre for Epidemiological Studies Depression Scale (CES–D) – Struchen et al. UCLA Loneliness Scale–Version 3 – Struchen et al. Brief Symptom Inventory (BSI)–18 – Hanks et al.	Struchen et al.'s mentored participants showed a significant increase in depressive symptoms after mentoring. No significant main or interaction effects on the UCLA Loneliness scale. In Hanks et al.'s study mentored TBI participants showed lower scores compared to controls on global severity, somatisation, depression, and anxiety, although the only significant difference was on somatisation. There was a notable, though non-significant, trend for mentored significant others to show higher levels of anxiety than the control group.
Life satisfaction and quality of life: Wisconsin Quality-of-Life Inventory (WQLI) (mentor) – Fraas and Bellerose Youth Quality of Life (YQOL) (mentee) – Fraas and Bellerose Satisfaction with Life Scale (SWLS) – Kolakowsky-Hayner et al.; Struchen et al. Medical Outcomes Study 12-Item Short-Form Health Survey (SF-12)	In the Fraas and Bellerose study the mentee showed improvements in all domains of QOL, most notably in sense of self and general QOL. The mentor showed improvements in self-esteem and self-actualisation. There were no significant changes in satisfaction with life in either study which employed the scale. Mentored TBI participants in the Hanks et al. study showed significantly better health-related quality of life on the SF-12 than controls.

Physical Functioning sub-scale – Hanks et al.	
Measures of disability management: Disability Rating Scale (DRS) – Kolakowsky-Hayner et al. Supervision Rating Scale (SRS) – Kolakowsky-Hayner et al.	Significant improvements were shown for both programme successes and failures on the DRS, specifically in terms of employability and level of functioning. Programme successes and participants in general showed significant improvements on the SRS, indicating a reduction in the level of daily supervision required.
Measures of behaviour management: Family Assessment Device (FAD) – Hanks et al. Short Michigan Alcohol Screening Tests (SMAST) – Hanks et al. Coping Inventory for Stressful Situations – Hanks et al.	On the FAD, mentored participants demonstrated significantly better behavioural control and reduced alcohol use compared to the control group. Significant others showed a notable, though non-significant, trend towards poorer general functioning than controls. The TBI group showed significantly less emotion-oriented coping and avoidance-oriented coping than controls, while significant others showed a notable trend towards less avoidance-oriented coping than controls.
Measures of participant feedback and programme satisfaction: Quantitative assessment of programme satisfaction – Fraas and Bellerose; Hibbard et al.; Coles and Snow; Kolakowsky-Hayner et al.; Struchen et al.; Hanks et al.	Most participants across all studies reported positive, enjoyable experiences, satisfaction with the programmes and their mentors, and would recommend the programmes to others. The majority also reported positive impacts on quality of life, ability to cope, mood, knowledge of brain injury, and social support. The majority of participants in the Struchen study felt that their mentor was able to help them increase their social activities and helped them feel less lonely.

Qualitative interviews and open-ended questionnaires – Coles and Snow; Moreci; Fraas and Bellerose; Hibbard et al.; Kessler et al.; Struchen et al.; Hanks et al.	In open responses, most participants were also extremely positive about their experience. Benefits included emotional and affirmational support; shared experience; increased confidence; social support; having someone to talk to; enhanced knowledge of brain injury and community services; learning about coping strategies; and receiving motivation and inspiration. Mentors reported a sense of value and enjoyment from helping others and making a difference. Some logistical issues were raised by mentors, such as problems scheduling meetings, relying on public transport and budgeting concerns. Important characteristics of mentors which participants reported included authenticity, friendliness, confidence, good listener, knowledgeable of resources and programmes, respectful, good communication skills, kindness, and experience with brain injury.
Log of mentee interest in specific topics – Kolakowsky-Hayner et al.	Mentees with a goal of returning to work were most interested in discussing job searching (1,027 times), vocational skill building (154 times), and rehabilitation (109 times). Those with the goal of returning to school were most interested in discussing the application process (206), disability resource centres (158), and time management (105). Participants interested in increased community participation wanted to discuss relaxation (379), family/friends (358), and relationship issues (354).

Return to employment or education – Kolakowsky-Hayner et al.	Of the 77 mentees who completed the programme, 42 (54.5%) had returned to work or education and 35 (45.5%) were considered programme failures. 30 successful participants had TBIs.
Contacts log – Hibbard et al.; Struchen et al.; Hanks et al.	The mean number of contacts with mentors in the Hibbard et al. study was 13 (SD 12). In the Struchen et al. study one pair met once, one pair met three times, two met four times, two met five times, four met six times, one met seven times, and one met eight times. In the Hanks et al. study the average number of contacts was 5.4 (range 1–66). The majority were by telephone, with only 11 face-to-face meetings after the initial contact. The meetings lasted for 5–15 minutes (36%), 16–30 minutes (30%), 31–60 minutes (19%), and > 60 minutes (15%).
Anecdotal evidence of impact – Struchen et al.	Struchen et al. noted anecdotal evidence of mentors assisting partners to improve their social behaviour. One mentee tended to talk inappropriately loudly in public and to use offensive language. This behaviour improved after the mentor raised their partner's awareness of it.

2.7 Discussion

I conducted this review to ascertain all the current evidence concerning peer mentoring for ABI, including the intervention design elements, outcomes, and effectiveness, with the aim of informing the development of a new ABI peer mentoring intervention. The review has shown that there are only a small number of published studies into peer mentoring after brain injury and a lack of

definitive randomised controlled trials. The evidence available comes from small-scale studies, employing different models of mentoring, methodologies, and outcome measures, all conducted in the United States or Canada. Quality assessment with the MMAT and Jadad scales showed that the RCTs had poorly designed or poorly reported randomisation and blinding, creating a risk of bias, while the other studies were of low-quality designs.

While the outcomes of the studies could not be pooled by meta-analysis due to the heterogeneity of the designs and outcomes, the RCTs in the review showed statistically significant improvements in perceived social support (Struchen et al., 2011), behavioural control, living environment, coping styles, alcohol use, and physical quality of life (Hanks et al., 2012). However, the trials also showed no improvements in community integration compared to controls (Hilari et al., 2021; Hanks et al., 2012), and even increases in depressive symptoms for mentored participants (Struchen et al., 2011). Quantitative results from other studies provided support for improving quality of life, participation (Fraas and Bellerose, 2010), community integration, and independence (Kolakowsky-Hayner et al., 2012). Two studies employed the Peer Mentoring Questionnaire to quantitatively assess the subjective benefits of mentoring, with high percentages of participants reporting positive impacts on knowledge of TBI, enhancing quality of life, improving outlook, improving mood, enhancing ability to cope, and satisfaction with mentoring partner (Hibbard et al., 2002; Hanks et al., 2012). Qualitative studies found that mentees reported the benefits of sharing experiences (Hibbard et al., 2002), and of emotional, affirmational, and informational support providing

encouragement, motivation, validation, and decreased feelings of being alone (Kessler et al., 2014).

There were differences between the populations included, with most involving mentors and mentees with the same form of injury (predominantly stroke or TBI). This makes it difficult to infer whether including participants with a range of ABIs as mentors and mentees would be successful. Fraas and Bellerose's study involved an encephalitis survivor mentoring a TBI survivor, but this was a single-pair case study, while Kolakowski-Hayner et al. included a mixture of neurological disabilities, and this meant that the results could not be interpreted as applying specifically to people with ABI. There were also differences in the demographics of the populations, including the time since mentored participants sustained their injuries, with some still in hospital, some recently returned to the community, and some several years post-injury. This makes it difficult to draw conclusions as to the optimum stage of recovery for delivering peer mentoring interventions.

The key characteristics of mentors identified by participants are important to note. These included authenticity, friendliness, confidence, good listening skills, knowledge of community resources, respectfulness, good communication skills, kindness, and experience with brain injury. These largely corresponded with, and added to, the mentor eligibility criteria pre-defined by the researchers. It will be important to select and screen mentors carefully for these traits and provide training on how to develop them.

The mode of delivery, settings, and goals of the interventions varied depending on the models employed by the programmes. For example, the early hospital

one-off visits employed by Kessler and Moreci had different goals to the more sustained community-based approaches used in other studies. This makes outcomes difficult to compare. There was also little information in the studies on the content of mentoring sessions themselves, so it is not known whether discussions in sessions kept to the intended topics or what activities took place. This is understandable, as sessions were largely intended to be private interactions between the partners, but a more rigorous approach to documenting session content would inform future research and help to determine the essential characteristics of ABI peer mentoring. It will be important to select the modes of delivery and the settings carefully, considering the goals of the project and the restrictions of a PhD study. It is most likely that a community-based setting would pose less restrictions than a hospital-based one. It is also likely that allowing partners to choose the most desirable and convenient setting for each of them would facilitate meetings.

There was considerable variation in the nature of the contacts between the pairs (with most studies allowing in-person, telephone, or email correspondence), the frequency of contacts, and the durations of the partnerships. It is important to implement these variables consistently in order to understand the factors which influence outcomes. The two studies which implemented a consistent approach to duration, frequency, and mode of contact were successful at bringing the partners together as planned (Fraas and Bellerose, 2010; Coles and Snow, 2011). These studies both required partners to meet once a week for ten weeks at a specific time and venue. However, it should be noted that these papers focused on single-pair case studies, so the approach may not be as successful in larger studies. It will be important to consider the issue when matching partners

and to consider their preferred means of contact. The focus of the intervention is also key to this issue. If the focus is purely on discussions, then phone conversations may be appropriate. However, if the goal is to participate in activities, then face-to-face contact in the community is essential. The participants' impairments are also a major factor in deciding on appropriate venues.

Although the studies described the criteria employed to match partners together, they provided little information on how easy this was to implement in practice. It can be inferred from the high levels of participant satisfaction with mentors that those who completed the programmes were matched together appropriately. However, future studies should provide more detailed information on the matching process and the reasons for unsuccessful matches and participant drop-outs. The key considerations must be the personal preferences of the participants and convenience of contact. It will be more important to consider the different variables if pairs are to meet in-person than if they are to make contact by telephone, videocall, or online.

There is much to be learned from the reports of the mentor training programmes. Mentors were trained very thoroughly and had follow-up training and support. The details of training programmes which are available from some of the authors can be adapted to inform the mentor training programme for this study. Training is a particularly important consideration and can be combined with a selection process to avoid recruiting unsuitable mentors who do not have the required characteristics. The feedback from mentors was positive, but there is little other evidence from the studies about the effectiveness of the training.

Each programme focussed on different training topics and there is a need to focus on topics specific to the goals of the intervention.

One of the key areas the studies in the review can help in planning my intervention design is in the logistical challenges described. These include scheduling of meetings, providing sufficient staffing, maintaining participant involvement, and making allowances for participants' cognitive difficulties. It is clear that it is important to make meetings as convenient as possible, provide support to both partners, match partners carefully, provide expenses and make the experience as enjoyable, rewarding and undemanding as possible.

The studies showed minor impact on measures of participation. The only study to look primarily at participation was Struchen et al.'s (2011), which employed a 'social peer mentoring' intervention. However, there were no significant improvements for the mentored participants in the number of social activities and interactions or satisfaction with social life. Despite this, the authors reported a trend in the mentored group towards increased satisfaction with social life over the previous month. The study also demonstrated some improvements in perceived social support and social integration. There were improvements on the participation domain of the Mayo-Portland Adaptability Inventory-4 (Kolakowsky-Hayner et al., 2012) and the CHART-SF occupation and social integration sub-scales (Kolakowsky-Hayner et al., 2012; Struchen et al., 2011), but mentored participants had lower scores than controls on the Community Integration Measure (Hanks et al., 2012). The increase in depressive symptoms found by Struchen et al. should be considered carefully and measures of mood and psychological wellbeing are advisable for the intervention. As Struchen et al. hypothesised, these symptoms may be

attributable to participants' increased awareness of their condition, so may decrease over time as participants learn how to manage their difficulties.

A particularly encouraging finding was the high level of satisfaction and positive feedback reported across the studies. These subjective appraisals may be as meaningful as improvements on standardised measures. For example, although no significant improvements were found on participation levels by Struchen et al. (2011), participants themselves felt that their mentors had helped them to increase their social activities and feel less lonely. Participants reported enjoyable and positive experiences with the programmes and satisfaction with their mentors. Other benefits included emotional and affirmational support; shared experience; increased confidence; social support; having someone to talk to; enhanced knowledge of brain injury and community services; learning about coping strategies; and receiving motivation and inspiration. Furthermore, mentors reported having gained a sense of value and enjoyment from helping others and making a difference.

The broad scope of this review was both a limitation and a strength. It could be a limitation in that I included studies of mixed methodologies and low quality, meaning that it is difficult to compare or pool their results and it could be misleading to report overall conclusions. However, the aims of the review meant that a broad scope was necessary in order to identify and analyse all the evidence regarding the design elements of ABI peer mentoring. The strengths were the thorough search, selection, and data extraction methods, with two researchers conducting each stage, verifying results, and discussing decisions.

Although no meta-analysis was possible, the review has found some evidence of effectiveness. There were also promising indications of the acceptability and feasibility of peer mentoring. It has also provided several clues as to the advantages and disadvantages of different design models and shown that there are numerous challenges inherent in delivery.

2.8 Systematic Review Update: 2022

The systematic review search was conducted in November 2016 so only papers published up to that time informed the subsequent elements of this project. An updated search was conducted in October 2022 and identified five further ABI peer mentoring studies published since 2016. The latest systematic review has recently been published (De Dios Perez et al., 2024). The studies are briefly summarised here, and the findings will be discussed along with the rest of the project in Chapter Six.

A pilot, feasibility RCT investigated the effectiveness of the Ontario Brain Injury Association (OBIA) Peer Support Programme (Levy et al., 2021). The programme operates a one-to-one, telephone-delivered peer mentoring service across Ontario, Canada. Pairs have weekly meetings lasting 20–40 minutes, in which they discuss brain injury-related issues. In the trial, mentees (n = 13) with moderate-to-severe TBIs were randomised to a weekly intervention or waitlist control group. The main outcomes were feasibility (based on recruitment, adherence, and retention), community integration, mood, health-related quality of life, and self-efficacy. Mentors and mentees also completed post-intervention qualitative interviews (n = 10).

A pilot feasibility RCT of peer befriending for people with aphasia after stroke (SUPERB), from which quantitative and qualitative papers have been published (Hilari et al., 2021; Northcott et al., 2022), matched people with aphasia after recent strokes to peer befrienders with mild–moderate aphasia >one year post-stroke. This was a single-blind, randomised study, with control participants receiving usual care. Participants in the intervention group were visited in their homes by peer befrienders six times over three months for meetings lasting approximately one hour. The meetings involved goal setting, conversations, problem solving, and trips out. Participants were assessed at baseline, 4 months and 10 months on measures of general health, psychological well-being, community integration, and communication confidence. Feasibility parameters included the proportion of people screened who were eligible, the proportion who consented, missing data, and attrition rates. The acceptability of the intervention was explored through qualitative interviews.

A qualitative, feasibility study of TBI survivors in New Zealand matched six mentees with moderate-to-severe TBIs receiving inpatient rehabilitation and soon to be discharged with six mentors who had been discharged from rehabilitation between one and five years previously (Kersten et al., 2018). Pairs were matched based on gender only, although mutual interests were considered. The meetings focussed on building rapport, exploring hopes, and supporting participation in activities. Pairs were intended to have six face-to-face sessions over three months, with the first meeting taking place pre-discharge at the rehabilitation unit and the other five at the mentee's home or in the community.

A qualitatively assessed, co-design study of stroke survivors in Bangor, Wales (Masterson-Algar et al., 2020), described as peer coaching, matched five people who had suffered strokes <six months previously to five peer coaches who were experienced stroke survivors. Pairings involved a maximum of six one-to-one meetings of up to one hour in public settings of the participants' choice. Each meeting had a specific focus and goal, with the overall aim of improving social and leisure participation.

Finally, a pilot mixed methods study in Canada investigated the impact of a structured single meeting between newly diagnosed brain tumour patients and trained volunteer 'veteran' brain tumour patients (Ozier and Cashman, 2016). Three veterans (>4 years post-diagnosis) received 15 hours of training and two were matched (according to tumour grade) to ten newly diagnosed patients (one veteran was matched to six patients and one to four). They met each new patient individually for a one-hour private meeting at a brain tumour clinic to discuss issues connected to the brain tumour and to provide information and resources.

The recent studies described above are not relevant to the material in the following three chapters because they were not published when my intervention was developed. However, they will enrich the discussion in Chapter Six and they further reinforced the original review's conclusions; that peer mentoring is challenging to recruit for and deliver, and the optimum design and outcomes are difficult to define. They strengthen the conclusions by virtue of improved methodology and better designed studies and add to the sense that participants derive value from peer mentoring, even if the effects are hard to measure quantitatively.

3 Chapter Three: Development and Design

3.1 Chapter Summary

This chapter describes the second study in this project, which involved Patient and Public Involvement and Engagement (PPIE) and qualitative interviews and focus groups. The chapter will begin by outlining the aims and objectives of this study and will explain the rationale in a brief introductory section. I will then outline the methods, including the procedures employed for graining ethical approval, identifying and recruiting participants, and for operationalising each element of this study, which involved PPIE workshops, interviews with TBI survivors, stroke survivors, carers, and professionals, and focus groups with ABI survivors. I will explain the methods used to analyse the large amount of qualitative data derived from this multi-stranded study, before presenting the results of each element.

3.2 Aims and Objectives

This phase of the study had the following aims and objectives:

- To explore the perspectives of
    - ABI survivors.
    - Carers/family members.
    - Brain injury service providers.
    - Peer mentoring researchers.
    - Professionals in related fields such as healthcare, social care, the independent sector, charity and leisure industries.
- This was intended to answer the following research questions:
    - Is a peer mentoring intervention important/needed?

- How it should be structured?
- Where, when, and how it should be delivered?
- What should be the key outcomes and goals?
- What are the logistical issues and risks that should be anticipated?
- Who should be responsible for delivery, e.g., NHS, social services, charities, etc?

3.3 Introduction

In Chapters One and Two, we have seen that there is a crucial need for interventions to help the huge population of brain injury survivors to adapt to life after injury. I have shown that there is a growing body of evidence to suggest that peer mentoring is a safe, enjoyable, practical, and adaptable way to boost self-esteem, enhance self-efficacy, and increase activity and participation levels. It is also clear from the previous studies in the field that one of the strengths of peer mentoring is its capacity for individual tailoring to the specific needs of mentees. This malleability also means that there are many ways mentoring can be delivered, depending on the requirements of the mentees. However, in designing a peer mentoring intervention to be evaluated scientifically, it is necessary to impose a structural framework so as to assess which elements are effective and which are not.

To evaluate the effectiveness of mentoring it is also important to have a clear idea of the outcomes to be assessed. However, previous studies have employed a broad range of outcome measures, which makes it difficult to compare results. There have also been mainly non-significant findings, suggesting that

the outcome measures used may have been insensitive to the benefits that have been widely reported by participants in qualitative evaluations.

In order to design the intervention for this study it was therefore necessary to decide between the myriad options for how, where, and when it would be operationalised, and what the goals for participants should be. To address these problems, I consulted people from key target populations to find out how they viewed the concept of peer mentoring and what they would want from a peer mentoring intervention. This chapter describes how this was achieved, the results, and the implications for the intervention design to be used in the next phase.

3.4 Methods

The development work consisted of two components:

1. **Patient and Public Involvement and Engagement (PPIE)**

Conducted in June–July 2015

The main purpose of this component was to understand the context for the delivery of peer mentoring, whether it should sit within NHS healthcare services or be separate from them, how it might be funded, how it could be operationalised in practice, and how it could help people to resume fulfilling lives. To do this I conducted group workshops with people with an active role, knowledge or expertise in supporting people with ABI to resume social and leisure activities. This included clinicians, rehabilitation providers, commissioners, solicitors, Headway staff, social care providers, leisure service providers, and brain injury survivors.

The PPIE workshops were the first part of the development work. I conducted them in the year preceding the PhD as part of a project to investigate peer mentoring for traumatic brain injury (TBI) survivors, on which I worked as a Research Assistant. The PhD followed on from this project and the PPIE work has been used to inform it.

2. Qualitative research

The purpose of this component was to gain a deeper understanding of the issues experienced by ABI survivors, their perceptions of what could help, what they thought about peer mentoring, and if/how they would like it to be delivered. This required exploring the personal perspectives of brain injury survivors and carers. Furthermore, to explore the issues relating to the delivery of peer mentoring on a deeper, more individual level to the PPIE work, I also sought the views of professionals with personal experience of delivering peer mentoring services, and professionals who provide brain injury services and could discuss issues relating to the prospective delivery of peer mentoring.

The qualitative research involved participants with a variety of injury types and severities in order to understand the application of peer mentoring in different contexts and for people who might normally be excluded from research studies (for example, because of physical or communication difficulties). Interviewing peer mentoring researchers and service providers gave crucial insights into factors which have been successful or unsuccessful in previous peer mentoring services, both for ABI and other conditions. Finally, the views of carers provided an alternative perspective on the needs of brain injury survivors from people who know them best and are important mediators for interventions.

The qualitative research consisted of five strands:

1. Interviews with TBI survivors: Conducted July–October 2015
2. Focus groups with ABI survivors: Conducted June 2017
3. Interviews with stroke survivors: Conducted July 2017
4. Interviews with service providers: Conducted October–November 2017
5. Interviews with carers: Conducted October–November 2017

Interviews were used to allow detailed exploration of individual views and experiences, while focus groups were employed to complement and enrich the information from the interviews. Unlike interviews, focus groups allowed for an exchange of views between participants and thus enabled deeper exploration of important issues. There were also pragmatic reasons for the use of interviews and focus groups; for example, it was practical and convenient to recruit several people at a time at the Headway Day Centre for the focus groups.

I conducted the TBI survivor interviews as a Research Assistant in the year preceding the commencement of the PhD. They were part of the same project to investigate peer mentoring for TBI as the PPIE workshops.

Two University of Nottingham MSc Rehabilitation students (AJR and AB) assisted me with the focus groups and stroke interviews. The students were supervised for their MSc dissertation projects by my primary supervisor (KR). AJR had previously worked at the local Headway Day Centre and used her contacts there to facilitate the organisation of the focus groups. AJR applied for ethical approval for the focus groups for her dissertation project and I designed the topic guides. We jointly conducted the focus groups, taking it in turns to

ask questions. We both recorded the interviews and AJR transcribed them. AB obtained ethical approval for the stroke interviews for her dissertation project and recruited participants through the contact network of KA, the co-funder of the project who ran a stroke support charity. I designed the topic guides and AB conducted the interviews by telephone. AB transcribed the interviews and provided me with the transcripts for analysis. Both AJR and AB used the data for their dissertation thesis projects. I discussed the results with them, but they conducted their analyses independently and their analyses and interpretations are not used in this thesis. All carer and professional interviews were conducted and analysed by me. Please see the 'Project Timeline and Contributors' section on pages xxiii–xxvii for further details.

The findings are reported following the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (Tong et al., 2007).

3.4.1 Ethical Approvals

Approvals for the qualitative research were granted by the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics Committee. The PPIE work did not require ethical approval or written consent.

3.4.2 Participant Identification and Recruitment

This section describes the recruitment process for each strand of the study. Examples of recruitment adverts, information sheets, and topic guides are in Appendices 6–9.

Patient and Public Involvement and Engagement (PPIE)

Stakeholders were identified as people with an active role, knowledge or expertise in supporting people with ABI to resume social and leisure activities. Most were known contacts of the primary supervisor and colleagues, including existing PPIE partners, people with TBI (former patients or research participants who had expressed interest in PPIE and given permission to be contacted), clinicians, rehabilitation providers, commissioners, solicitors, Headway staff, social care providers and leisure service providers. These people were invited by email or letter. They were also asked to suggest other experts as potential participants. Delegates needed to be able to travel to the meetings and participate in a three-hour session with breaks.

Qualitative Research

TBI survivor interviews: Participants were required to have sustained a TBI between 6 months and 10 years previously, be 18 years old or over, to live in the community and be able to participate in a spoken interview (no exclusion criteria). A target total of twenty participants was pre-specified so as to gather a broad range of views and experiences. They were recruited via the following methods:

- Approaches to PPIE networks, and former research participants of my supervisor who had expressed interest in being contacted about future research.
- Advertising on the local branch of Headway's website and social media pages.
- Posters displayed in the local Headway Day centre.

Potential participants were provided with hard copies of the participant information sheet and consent form. It was explained that participation was entirely voluntary and that they could withdraw at any time. For those who provided their written consent, interviews were arranged at a time of their convenience.

Focus groups with ABI survivors: People attending a local Headway Day Centre were invited to take part in the focus group taking place that day. Anybody with an ABI attending the day centre was eligible for recruitment. Attendees were all over 18 years old and could have any form of ABI (there were no exclusion criteria). They were recruited at the centre via posters, advertisements on the Headway Group's website/social media channels, and by approach on the morning of the focus group. Hard copies of participant information sheets were provided in-person to interested parties and they were given the opportunity to ask questions. All participants signed consent forms prior to commencing the focus groups. There was a target of 3–10 participants for each group.

Stroke survivor interviews: Stroke survivors were recruited via the chief executive of a stroke charity (who was a contact of the supervisory team) with a large contact network of severe stroke survivors (including people who had suffered brain stem strokes and had been in minimally conscious states). Potential participants were approached via email or telephone and asked to take part in a one-off interview lasting approximately 30–90 minutes. They were required to be at least one-year post-stroke (with no upper limit), aged between 18 and 75 and to have the capacity to participate in an interview. Participants were excluded if they had severe aphasia, anterograde amnesia, were unable to

concentrate for 30–60 minutes, or did not have access to a telephone or the internet to conduct the interview. A target total of ten participants was pre-specified for practical purposes.

Service provider interviews: Participants were 18 years old or over and had experience of one of the following (there were no exclusion criteria):

- Managing and/or co-ordinating support/community services at Headway or other ABI charities.
- Co-ordinating peer mentoring services for people with any disability.
- Conducting academic/clinical research into peer mentoring for any disability.

I identified some participants based on previous professional contacts and experience of working in the field. These people were approached directly and provided with information on the project. Others were identified by finding the relevant contacts on the websites of ABI charities. I aimed to recruit 5–10 participants for practical purposes.

Carer interviews: Participants were aged 18 or over and a spouse, significant other, family member or friend of an ABI survivor (there were no exclusion criteria). Carers were recruited via adverts on the websites, facebook, and twitter pages of Headway, the Stroke Association, and Different Strokes, and printed versions at local support groups. Advertisements and posters directed people to contact me by telephone or email. Those expressing an interest were then contacted and provided with the participant information sheet and consent form. I explained to people that participation was entirely voluntary and that they could withdraw at any time. People who returned a signed consent form

were then contacted to arrange an interview. I aimed to recruit 5–10 participants.

3.4.3 Procedure

This section describes the procedure for conducting each strand of the study.

Patient and Public Involvement and Engagement (PPIE)

There were three consultation sessions at the University of Nottingham's Lakeside Arts Centre. The days ran from 10 am to 1 pm, with presentations, group activities, and discussions lasting 15–30 minutes each. There were breaks for lunch and refreshments. The sessions were recorded on a digital voice recorder, and due to the length and amount of irrelevant content in the recordings, I made detailed notes of relevant sections rather than full transcriptions.

The activities, presentations and discussions addressed the following issues:

- Defining a successful peer mentoring intervention
- Context of delivery in relation to other services
- Qualities of a good mentor
- Content of mentoring sessions
- Theoretical background for peer mentoring
- Developing goals
- Risk, safety, and governance issues
- Access and recruitment
- The scope and remit of mentoring
- Support for mentors

The workshops were facilitated by a member of the research team, who was an Implementation Research Fellow at the University of Bangor. I presented a summary of the evidence for peer mentoring after TBI, co-facilitated the activities, and group discussions, recorded sessions, and took notes.

Interviews

Potential participants were all provided with hard copies of the participant information sheet and consent form. It was explained that participation was entirely voluntary and that they could withdraw at any time. For those who gave written consent, interviews were arranged at a time of their convenience.

Interviews had no fixed duration but were not intended to last more than 90 minutes. For convenience all interviews were intended to be conducted by telephone, but participants were offered the option of face-to-face interviews at a convenient location if they preferred. Telephone interviews were conducted by the researcher (MSc student AB for the stroke interviews and me for all others) from a private office at the University of Nottingham or the researcher's home. Stroke participants with aphasia were offered the option of conducting the interview by online messaging.

All interviews were recorded on a voice recorder and transcribed verbatim using a professional transcription service. Interviews conducted by online messaging were automatically transcribed. Transcriptions were anonymised and stored on a secure University of Nottingham server.

The interviews were semi-structured and explored the effects of the participant's injury (and its impact on the carers); experiences of engaging in social and leisure activities before and after injury; experiences of support and

rehabilitation; experience of working in ABI support services and knowledge/experience of peer mentoring (service provider/researcher participants); and opinions on peer mentoring and how it should be designed and implemented.

Focus Groups

There were three focus groups, all with identical topic guides and schedules, conducted in a private room at a Headway Day Centre. The topic guides were semi-structured and explored the effects of the participants' injury; experiences of engaging in social and leisure activities before and after injury; experiences of support and rehabilitation; and opinions on peer mentoring and how it should be designed and implemented.

The groups were scheduled to run for approximately 90 minutes and were facilitated by me with the support of an MSc Rehabilitation Psychology student. Participants sat around a table in an informal group setting, and the student and I introduced the aims of the session and asked questions alternately.

All focus groups were recorded on a voice recorder and transcribed by the student researcher. Transcriptions were anonymised and stored on a secure University of Nottingham server.

3.4.4 Data Analysis

This section describes the data analysis process for each strand of the study.

Patient and Public Involvement and Engagement (PPIE)

The analysis of data from the PPIE component was informed by the a priori structure of the workshop sessions, which were intended to investigate the following main topics:

- Defining a successful peer mentoring intervention.
- Defining the key traits of good mentors.
- The relationship between peer mentoring and healthcare services.
- Elements of risk in a peer mentoring intervention.

The workshops were too long to transcribe verbatim, so I listened to the recordings, made detailed notes, and referred to flipchart notes from the sessions.

I produced lists of results for each topic that was discussed. This produced long lists of ideas, some of which were slight variations of the same theme. I then combined related ideas into single themes and grouped the results from all the sessions into the four main categories outlined above.

Qualitative Research

This was partly a deductive process, because the main topics of discussion were specified a priori in the topic schedules, while also allowing for new themes to emerge inductively. I analysed the data independently, with the help of discussions and exchanges of information with the MSc researchers regarding the stroke survivor interviews and focus groups.

The analysis process followed the seven-step framework method, as defined and described by Gale et al. (Gale et al., 2013). This method was chosen for its

suitability for use with both inductive and deductive analysis, lending itself well to generating themes related to the prespecified topics, while also generating new themes which had not been anticipated. As the qualitative analysis employed a pragmatic approach designed to analyse the practicalities of peer mentoring and answer specific practical questions related to implementation and outcomes, qualitative methods underpinned by philosophical ideologies and employing a more predominantly inductive approach, such as grounded theory, phenomenology, and discourse analysis, were not considered appropriate. Framework analysis methods have been shown to be well suited to datasets collected to address specific topics and key issues (Klingberg et al., 2024) and have been employed by researchers in a broad range of fields, such as global health (Klingberg et al., 2022), health services (Heath et al., 2012), and health professions education (Balmer et al., 2021).

The analysis procedure, in accordance with the seven stages of the Framework Method, was as follows:

Step One: Transcription.

The interviews with TBI and stroke survivors were transcribed by an external transcription service. Long pauses, laughter and unclear speech were noted on the transcripts. After receiving the transcripts, I read them while listening to the recordings, anonymised them by removing identifiable names and places, and corrected any content which had been incorrectly transcribed or marked as unclear. I transcribed the interviews with carers and service providers myself using online transcription software. The focus groups were too long to produce verbatim transcriptions, so I listened to the recordings and wrote detailed notes.

Step Two: Familiarisation.

I read transcripts and listened to recordings three–four times each while making notes of observations and recurring topics.

Step Three: Developing a working analytical framework.

As the process was partly deductive, the framework was specified a priori and was informed by the findings from the PPIE workshops, by the findings of previous studies on peer mentoring for ABI and other disabilities (including the studies in the systematic review presented in Chapter Two and the literature review presented in Chapter One) and by the Template for Intervention Description and Replication (TIDieR) checklist, which provides a framework for the reporting of all required elements of the intervention design (Hoffmann et al., 2014).

The key topics were:

- Important outcomes/goals
- Activities
- Risks/safety/logistical issues
- Mentor training
- Support needs of mentors and mentees
- Social and leisure re-engagement
- Characteristics of a good mentor
- Mode of delivery
- When/how long after injury?
- Duration, number and frequency of sessions
- Matching criteria

Because the aim of the intervention is to change the behaviour of mentees by helping them to increase participation, the themes and sub-themes were

mapped onto the components of the behaviour change wheel (BCW) (Michie et al., 2011). The BCW is a framework based on the idea that behaviour change is predicated on three main components:

- Capability: An individual's psychological and physical capacity to engage in the activity concerned.
- Opportunity: All the factors that lie outside of the individual that make the behaviour possible or prompt it.
- Motivation: Internal processes that energise and direct behaviour, not just goals and conscious decision-making. Includes habitual processes and emotional responding, as well as analytical decision-making.

According to the BCW, to change a participants' behaviour we must influence one or more of these areas. Therefore, mapping the themes and sub-themes to the BCW allowed me to show whether aspects of the intervention influenced the participants' capability, opportunity, or motivation, and could subsequently affect behaviour change, such as participation in areas of life. Furthermore, to understand how the intervention could modify the impact of impairment on the person's activities and participation, the findings were mapped to the International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2002), which was discussed in Chapter One.

Step Four: Coding.

I labelled sections of the transcripts and notes with topic headings to describe important ideas related to the framework.

Step Five: Applying the analytical framework.

I linked coded sections to the overarching topics and created lists of sub-topics and illustrative quotes for each individual interview participant or focus group. These were tagged with codes for the relevant elements of the BCW, the ICF, and the TIDieR checklist.

Step Six: Charting the data into the framework matrix.

I created tables in Microsoft Word and Excel for each strand/participant group, which cross-referenced each interview participant/focus group (in rows) to each sub-heading, along with associated quotes.

Step Seven: Interpreting the data.

The final step was to synthesise the results from each strand/participant group and to combine/refine the sub-headings. I produced a combined matrix, pooling the data under each sub-heading and/or re-assigning the headings where appropriate. The process was complete when all concepts and quotes labelled as of importance were included under headings and sub-headings which summarised the key findings. The headings and sub-headings were tagged with the elements of the BCW, ICF, and TIDieR checklist that applied to them.

3.5 Results

This section firstly provides details of participant numbers and demographics, before describing the results of the data analysis.

3.5.1 Participants

All initials used for participant identification are pseudonyms.

PPIE Workshops

Three sessions took place in June and July 2015. In total there were thirteen participants, including five men and eight women. They included five occupational therapists (OTs), a rehabilitation nurse, three TBI survivors, one support worker, one solicitor, one former brain injury case manager/current IT specialist, and one disability sport engagement advisor. Twelve participants were white British and one was white Spanish. Details of participants' ages were not recorded.

TBI Survivor Interviews

Twenty interviews were conducted between July and October 2015. Participant demographics are provided in Table 3.1.

Table 3.1. TBI survivor interview demographics

ID	Gender	Age	Ethnicity	Time since injury (months)	Education	Cause of injury	Severity of injury (self-reported)
AA	M	63	White British	70	Degree	RTC* (car)	Moderate-to-severe
AB	M	23	White British	54	Degree	RTC (car)	Severe
AC	M	39	White British	43	Degree	RTC (bicycle)	Minor
AD	F	29	White British	18	Degree	Fall at home	Minor
AE	F	44	White British	64	Degree	RTC (car)	Severe
BA	M	Not stated	White British	108	Degree	Assault	-
BB	F	Not stated	White British	31	Degree	RTC (car)	Minor
BC	M	33	White British	77	Degree	RTC (car)	Severe
BD	M	22	White British	37	Degree	RTC (car)	Moderate-to-severe
BE	M	45	White British	72	Higher education	RTC (car)	Severe

CA	M	41	White British	31	Degree	RTC (bicycle)	Severe
CB	F	45	White British	54	Higher education	RTC (car)	Moderate
CC	M	24	White British	40	Degree	-	Severe
CD	M	Not stated	White British	32	Degree	Assault	Moderate
CE	M	35	White British	50	Degree	Fall	Severe
DA	F	38	White British	36	Degree	Sports injury	Severe
DB	F	49	White British	41	Degree	Assault	Severe
DC	F	27	White British	97	GCSE	RTC (pedestrian)	Severe
DD	M	33	White British	43	Higher education	RTC (car)	Severe
DE	M	26	White British	33	Degree	RTC (car)	Severe

*RTC=Road traffic collision

There were 13 males (65%) and seven females (35%). The mean age of participants was 36.24 years (SD = 10.62; 3 missing). The mean time since injury was 51.55 months (SD = 22.77). The mean duration of the interviews was 66.8 minutes (range 41–103.5; SD = 19.01).

Stroke Survivor Interviews

Eight interviews were conducted by telephone and two by online messaging in July 2017. Participant demographics are provided in Table 3.2.

Table 3.2. Stroke survivor interview demographics.

ID	Gender	Age	Ethnicity	Education	Time since stroke (months)	Type of stroke	Country of residence
SA	F	46	White British	Degree	89	Ischaemic	UK
SB	F	53	White British	Degree	68	Ischaemic	UK

SC	F	50	White British	GCSE	62	Ischaemic	UK
SD	F	38	White British	Degree	Not provided	Not provided	UK
SE	M	61	White French	Other/vocational	85	Haemorrhagic	France
SF	F	54	White British	Higher education	84	Ischaemic	UK
SG	F	42	White Finnish	Degree	270	Not provided	Finland
SH	M	46	White British	Degree	66	Haemorrhagic	UK
SI	F	47	White British	Higher education	72	Not provided	UK
SJ	F	51	White Australian	Degree	82	Not provided	Australia

There were eight female interviewees (80%) and two males (20%). The mean age of the participants was 48.80 years (SD = 6.18). The mean time since stroke was 97.56 months (SD = 61.63; 1 missing). The mean duration of interviews was 33.19 minutes (range 26–46; SD = 5.77; two online).

Service Provider Interviews

Seven telephone interviews were conducted between September and November 2017. Participant demographics are provided in Table 3.3.

Table 3.3. Service provider interviews participant characteristics.

ID	Gender	Ethnicity	Professional role
PA	F	White British	Charity Chief Executive
PB	F	White British	Day Centre Manager
PC	F	White British	Day Centre Services Manager
PD	F	White British	Charity Mentoring Coordinator
PE	F	White British	Charity Support Coordinator
PF	F	White British	Stroke survivor, expert speaker, and advocate
PG	F	White Spanish	Researcher and NHS Occupational Therapist

The mean duration of the interviews was 71.43 minutes (range 46–92 minutes; SD = 16.19).

Carer Interviews

Six telephone interviews were conducted between October and November 2017. Participant demographics are provided in Table 3.4.

Table 3.4. Carer interview demographics.

ID	Gender	Age	Ethnicity	Relation to injured person	Injured person's gender	Injured person's age	Type of injury	Time since injury (months)
KH	F	58	White British	Mother	F	35	Hypoxia (heart attack)	63
TT	F	55	White British	Mother	M	25	TBI (fall)	106
PS	F	41	White British	Wife	M	60	Stroke	70
TG	F	37	White British	Wife	M	37	Hypoxia (Cardiac arrest)	73
SO	F	38	Asian British	Wife	M	41	Stroke (haemorrhagic)	13
NH	M	66	White British	Father	F	35	TBI (horse riding accident)	87

There were five females (83%) and one male (17%). All except one were of white British ethnicity. All except one (a father) were the wife or mother of the injured person. The mean age of carer participants was 49.17 years (SD = 11.07). The mean age of the person with brain injury was 38.83 years (SD = 10.62), with a mean time since injury of 68.67 months (SD = 28.52). The mean duration of the interviews was 60.83 minutes (range 47–87; SD = 12.43).

Focus Groups with ABI Survivors

Three focus groups were conducted in June 2017 at a local Headway Day Centre. Each group lasted approximately 90 minutes. Thirteen people

participated across the three sessions. Participant demographics are provided in Table 3.5.

Table 3.5. Focus group participant demographics.

ID	Gender	Age	Ethnicity	Injury type	Injury cause	Time since injury (months)
1A	M	45	White British	TBI	RTC* (car)	360
1B	M	56	Black Caribbean British	TBI	RTC (pedestrian)	444
1C	M	54	White British	TBI	RTC (car)	437
1D	M	66	White British	TBI	RTC (car)	258
2A	M	53	White British	TBI	RTC (motorcycle)	380
2B	M	54	White British	TBI	Assault	132
2C	M	48	White British	TBI	Work accident (roofing)	97
3A	F	30	White British	Brain tumour	N/A	31
3B	M	53	White British	TBI	RTC (car)	444
3C	M	26	White British	TBI	RTC (car)	99
3D	M	41	White British	TBI	Assault	34
3E	M	42	White British	Hypoxia	Complication at birth	505
3F	M	65	White British	Stroke	Subarachnoid haemorrhage	325

*RTC: Road traffic collision

The mean age of the participants was 48.69 years (SD = 11.42). The mean time since injury was 272.77 months (range 34–505; SD = 165.94).

3.5.2 Analysis: PPIE Workshops

Part One: Defining a Successful Peer Mentoring Intervention

The first workshop session sought to define a successful peer mentoring intervention. Delegates were split into three groups to generate ideas for key attributes the intervention should possess. Each group then presented their ideas and discussed them. The following is a list of the main topics identified after analysis:

- Helps to improve outlook to recovery and life with brain injury.
- Has broad impact across a variety of areas.
- Is adaptable to the personal preferences of participants.

- Has a clear focus and aims for each individual.
- Enhances self-confidence.
- Reduces stress, anxiety and depression.
- Aids achievement of personal goals.
- Is enjoyable for participants.
- Facilitates increased social and leisure activities.
- Is convenient and easy.
- Enhances personal relationships.
- Enables mentees to make better judgements and decisions regarding their recovery and everyday life.

Part Two: Defining the Key Traits of Good Mentors

The aim of this session was to discuss what kind of person would make a good peer mentor. Delegates were split into groups to generate ideas for the characteristics and skills a mentor should possess, before coming together for a discussion which produced a combined list. After analysis, the topics were refined into the following list:

- Brain injury survivor.
- Good insight and self-awareness.
- Motivated.
- Self-confident.
- Good organisational skills.
- Experience of adapting to life with the injury.
- Good people skills.
- Independent.

- Knowledge of services and resources.
- Good understanding of a mentor's responsibilities.

Part Three: Embedding of Peer Mentoring in Healthcare Services

This section of the workshops asked participants to consider the relationship between the proposed peer mentoring service and rehabilitation, health, and social care services. Participants were asked to consider whether the service should be embedded within professional services or be entirely separate. Group discussion generated the following key points:

- Personal experience of injury is the most important element.
- Risk, implementation, training, and monitoring issues may mean the service should be embedded in the NHS to some extent.
- The service should be about the support mentors can provide which professionals cannot.

The strong consensus was that experiential knowledge was most important. Peer mentoring is not a professional service, but instead offers an alternative, complementary approach to professional therapy. The following key issues were raised in group discussions: the need for a professional safety net (so some embedding must be present) and the timing of the intervention (earlier intervention will require a more embedded model in partnership with rehabilitation services, whereas for people who have progressed beyond rehabilitation it can be less embedded).

Part Four: Elements of Risk in a Peer Mentoring Intervention

A group discussion elicited key risk and safety issues, before identifying ways of minimising them. The following risks were identified:

- Lack of clearly defined structures and boundaries.
- Lack of support for mentors.
- Impatience from mentors.
- A 'you must do this', 'be like me' attitude from mentors.
- Mentors having to deal with awkward questions.
- Sharing of alcohol or drugs.
- Inappropriate/risky activities.
- Inappropriate behaviour, such as sexual pressure or financial manipulation.

The following elements were identified as important ways of minimising these risks:

- Provide a clear structure and focus.
- Support for mentors and mentees.
- Tailor the intervention to the mentee's needs primarily.
- Provide training and supervision for mentors.
- No alcohol or drugs.
- Provide clear boundaries on the discussion of financial and sexual issues.

3.5.3 Analysis: Interviews and Focus Groups

This section presents the themes that were inductively generated in the interviews and focus groups under each main area of the framework. The main areas of the framework were the following:

- Key attributes of peer mentoring.
- How peer mentoring helps.
- Outcomes of peer mentoring.
- Characteristics of a good mentor
- Mode of delivery
- Activities
- Risk, safety, and logistical issues
- Mentor training
- When? How long after mentee's injury?
- Duration of service/number of meetings
- Frequency of meetings
- Duration of meetings
- Matching criteria
- Context of delivery

Key Attributes of Peer Mentoring

The following two main themes were identified for this topic: safety and simplicity.

Safety

The safety of the intervention was a key consideration, especially if pairs were to be unsupervised for meetings. Participants felt that professional supervision was essential for both mentees and mentors:

> *"And so, I do think a safety net is absolutely vital, for both sides as well."* BC

It was considered important for a third party to know when and where meetings were scheduled so they could check that people had got there and back safely:

> *"It could be, right okay, you want to see us three times a week, okay these fit in with that person, and this person, because they'd both have to agree the days. This time of day, and then somebody obviously knows that's what's happening, that's where they're at. So, if they haven't called at a certain time."* AE

Ensuring that all meetings are properly documented would add to the sense of security for participants:

> *"...if you're going to have that kind of one-to-one going off and doing something together, that does need to be – there does need to be a record of that, just because you never know."* CB

Simplicity

While ensuring that the intervention is monitored and documented is important for safety, it is also important to keep things simple and straightforward. Many people stated that peer mentoring does not need to have overly ambitious goals:

> *"Well sometimes less is more in terms of what you're trying to achieve and what you're trying to get the person to achieve."* CD

The main benefit is from talking to someone who understands the mentee's situation:

> *"Just simple things as well...just day-to-day managing as well, and having somebody there who is not going to turn around and go, 'Oh, that's weird, how do you cope with that?' They're going to say, "Yeah, I know exactly." And they'll probably pre-empt what you're going to say."* AD

Simple activities were considered important in facilitating engagement with the intervention, rather than focussing on activities that might be difficult and overwhelming:

> *"It could start off with something like even just going to the park together or sitting down and playing a board game together."* DA

Relation to framework

These attributes of safety and simplicity relate to the BCW component of *opportunity*, in that they facilitate engagement with the intervention. They are also aligned with all elements of the TIDieR checklist because they should be considered when designing all aspects of the intervention.

How Peer Mentoring Helps

The following themes were identified under this topic: sharing experiences; empathy and understanding; encouragement; reassurance; and information.

Sharing Experiences

The idea of simplicity was reflected in the primary importance of sharing experiences as the key mechanism of peer mentoring. Just talking to somebody

who has been through similar experiences is considered to have transformative power:

> *"Sharing of experiences; it's such a powerful thing it just really makes a tremendous difference to how brain injury survivors sometimes perceive themselves and their potential after brain injury."* PA

The knowledge that they are not alone would be a huge boost to survivors' mood and self-worth. It also provides the practical benefits of learning from someone else's experience:

> *"After a stroke you feel very alone and sharing can help with that (pause) also you have to find different ways to do regular stuff after the stroke and most of the times you cannot figure out how to do this, but by sharing you can see how others cope and learn from that."* SF

Service providers understood that survivors often have more credibility with patients when sharing advice which comes from experience:

> *"I think sometimes where we're trying to persuade someone to examine their fatigue level, for example, and try out a different way of operating, we might have limited success. Whereas they might talk to a peer who has resisted that but decided to give it a go and found it had an impact and can share that."* PA

Empathy and Understanding

Shared experiences create empathy and understanding, which are integral to the feelings of normality and hope provided by a peer mentor:

> *"And the understanding as well that this is normal, that whatever you experience you might find it extraordinary, but it's a part of the process of recovery."* AA

An important part of this is knowing that there is someone who understands, no matter what the issue:

> *"And no matter how daft you think your question is or you just want to let off some steam and say, "I'm really struggling to cope with this," somebody is there to – they're not there to judge, they're there going, 'Yeah, I remember that happening to me.' And it doesn't necessarily need to be giving advice, it's just nice having somebody there who understands one hundred percent what you're saying because they've been there."* AD

This provides a unique form of support, which is different to that provided by both professionals, who are outcome-oriented, and family members, who are intimately involved in the situation:

> *"I think just listening and understanding and empathising, I think rather than the professional who's trying to sort of get you to a certain standard of recovery. I think if you talk to someone who's been through it, I think it can help you emotionally, more like a friendship than a professional relationship."* SB

Participants described the value of just being able to talk and even complain about things to someone who understands and does not judge them harshly:

> *"It's nice knowing someone's there, just to talk to. Even if it's, 'Oh I'm not feeling not very good today.' You know, helping to you pick you*

back up. Sometimes I find it hard to talk to friends and family, you don't want to burden them, do you?" FG 2

Encouragement

A further benefit of the reassurance provided by knowing you are not alone is the encouragement of knowing that recovery is possible. Mentors can show that, even with a brain injury, it is still possible to live a fulfilling life:

"Seeing people who've had a brain injury, 'Gosh they're working, wow!' That's something I could probably do and that also gives you confidence and encouragement that there is life still after, no matter what you've been through." FG 2

Participants felt that this can provide confidence and motivation with activities and participation:

"And it's the encouragement of knowing that you've got support there and you're not on your own is a really big thing. And it's getting the confidence to do what you used to do or do something a little bit different and work up towards what you did before your injury." AD

Encouragement and motivation from a peer mentor can have the added benefit of being based on realistic expectations. This is important to protect against disappointment if expecting too much too soon:

"I was going through it. I used to do this, but now I do. This journey, one that you can make isn't impossible. You can get there but it takes time. And again, going back to kind of limiting expectations, not trying

to run before they can walk. reiterating that this is a long process. It does come in the end but be patient." PC

Reassurance

As well as encouragement, mentors can provide reassurance that the effects of the injury are normal and other people have experienced them too:

"It would have been nice to know and have somebody there who could turn around and say, 'Well actually, you are going to feel – or you may feel this about going out and going into a noisy environment'." AD

Information

Participants felt that mentors could be a reliable source of information about coping strategies for the unexpected effects of the injury:

"I think from my own point of view at the moment it would be more information on what to expect and what not to be so shocked about and what not to be wound up about." BE

First-hand information about navigating the healthcare system is also important:

"Yeah, just what to expect from the NHS, just maybe explain that at the beginning." CA

Advice and information on returning to employment and claiming benefits is also particularly helpful from someone with practical experience of the processes after brain injury:

> *"Yeah, it would've been nice to have known that, when I tried and forced myself to go back to work and I got really ill and collapsed, there were actually things I could've claimed."* AE

> *"I still wanted to work, so information on how to get back to work."* SA

Finally, a mentor can pass on information about meeting other people with brain injury and finding groups, services, and places to get involved in activities:

> *"Information on activities I could do. I want to be around people like me and I had no idea how to reach people like me apart from going online."* SA

Relation to framework

This topic area relates to the mechanisms by which peer mentoring can help mentees and facilitate change and growth. Therefore, the topics influence the mechanisms that will be built into the design of the intervention. They relate to the way a mentor can help to influence the ICF components of *impairment*, *activities*, and *participation*, and the BCW components of *capability* and *motivation*. The TIDieR components of 'Why', 'What' and 'Tailoring' should also be considered in relation to the concepts.

Outcomes of Peer Mentoring

The following main themes were identified under this topic: personal goals; mood; social and leisure participation; confidence; and coping strategies.

Personal Goals

It was considered important that peer mentoring has one or more specific outcomes for the mentee to aim towards:

"I think that's what mentoring is because if you're mentoring somebody, you're mentoring them towards an end." PA

To this end, a mentor can help their mentee to identify goals that are important to them and work towards them:

"The purpose of the peer work and the peer is to help identify and shape goals." PG

The goals will be different for each mentee, depending on their stage of recovery, their interests, and their priorities:

"I mean, it's completely up to the individual...I was concentrating on walking to the corner shop and back and things like that. So going to a brand new environment. It's different for everyone but I think it should be gradual." AD

Mood

Emotional support from a mentor was considered to be important for alleviating the anxiety and depression that are common after ABI. Learning to cope with anxiety was said to be an important goal for many people:

"I think emotionally it would have been helpful. I was very, very anxious after my stroke so I think it would have helped me emotionally." SB

This stroke survivor felt that a mentor could have provided support and information about the mental health issues to expect, which would have helped them to cope:

"Helping with the mental health issues associated with a life changing event...the depression, the post-traumatic stress, none of which I got any support with at all, any warning." SA

Social and Leisure Participation

The loss of friends after brain injury has an enormous impact on quality of life, mood, and self-esteem. A mentor can help with this by providing someone to talk to and spend time with:

"There may be people who lose their social circle as a result of it. I think I've lost touch with people as a result of it. I've got a full social life, but I think there are people who I've lost contact with who I miss. To have someone to go out with, that could be invaluable again." AC

Another tangible impact of mentor support is improving participation in activities. A mentor can help with this in ways that clinical rehabilitation services cannot always do:

"The NHS, the OTs, they can't necessarily do things like that, like all the time or anything. So it'd be good to like do social activities and even, you know, including talking or any reading or even going out for a walk." DC

A mentor can also help by passing on strategies that have helped them to cope with social situations, which can be very difficult for many people:

"Yes, it would help someone who has had a brain injury get back into socialising and how to deal with issues, you know, get methods involved, strategies involved in dealing with socialising and stuff like

that. I think one on one support and having someone who's been through it will have a massive impact on people's attitudes." DD

A mentor with specific knowledge, skills and experience helps a mentee focus on activities of interest to them:

"The person with the brain injury could have time with somebody like a skilled person or a trained person who could help them to talk about what were they like before, what things did they like to do, what things did they enjoy doing, what things were they good at, that kind of thing." CB

Confidence

Importantly, enhancing confidence was considered an enormous potential benefit of the support, reassurance and understanding from a peer mentor. This confidence could then help in other areas of life:

"I think it would work in getting peoples' confidence back and giving them a life again. And I think that would aid them in doing everything". CE

A key role for a mentor is to provide the encouragement to get people started on an activity they enjoy but do not have the confidence to do alone:

"First confidence. You can do this! Would you like to do this? You'd enjoy it. Why don't you do it? Because I don't have the confidence. Look, let me show you and get you started off. Perhaps when you learn that you can do it and you'll gain confidence. You'll enjoy it and you'll want to take it further." FG 2

Coping Strategies

Although clinical rehabilitation aims to provide coping strategies, participants felt that mentors can share their experiences of which ones have worked for them, and that this provides real-world authenticity and reassurance.

> *"Just because they'd know where the person's coming from, so they could help with coping methods and the problems they've encountered and how they got round them."* AB

Relation to framework

These topics are key to the outcomes to be targeted by the intervention design. They relate to the ICF components of *impairment*, *activities*, and *participation*, and to the BCW components of *capability* and *motivation*. They are also integral to the TIDieR elements of 'Why', 'What', 'How' and 'Tailoring'.

Characteristics of a Good Mentor

The following main themes were identified under this topic: good listener; positive attitude; honesty; understanding and patience; willing to learn; insight and self-awareness; and nurturing attitude.

Good Listener

This was cited by most participants as an essential characteristic for a peer mentor. They discussed what being a good listener involves, which means actively engaging with what they have to say and how they are feeling:

> *"I think it's really important that they're not wanting to talk about themselves all the time that they're a good listener."* SB

Empathy was frequently cited as a key part of being a good listener. This involves really listening and understanding what the person is going through:

> *"Empathetic listening ear, not to be too entrenched and to be open minded, to be willing."* SA

> *"Empathy, empathy, empathy...so you're listening to the person and you're letting them do all the talking."* SF

Positive Attitude

A positive attitude to recovery was considered particularly important for a mentor. One participant described how it was important to convey an upbeat attitude to the mentee regarding life with a brain injury:

> *"It's important that they're positive no matter what their disabilities are or what their recovery has been. That they are positive that they don't have, they may have had depression but it's important that they don't have it when they are meeting the other person and they're not very (depressing) about life, about stroke."* SD

Another benefit of a positive attitude was said to be the willingness to try new activities with the mentee:

> *"They've obviously got to have a positive attitude and an imagination. Someone who's willing to try anything. Try it, whether they might like it, might not like it. Outgoing person. Always have a positive attitude."* FG 2

Honesty

It was considered important that mentors are honest about both the positive and negative aspects of life with brain injury.

> *"Willingness to share experiences and be honest but not hurt anyone's feelings, not to be judgemental."* SJ

Understanding and Patience

Participants emphasised the importance of mentors being patient and understanding of the mentee's impairments. However, it was also considered necessary for mentors to provide honest feedback even if it is unflattering:

> *"Understanding and patience, but also not too much patience. If someone's behaviour is bad, you know what I mean? It needs to be truthful all the time."* FG 1

Willing to Learn

Nobody can be the perfect mentor and have all the knowledge and skills required, so it is important that people are willing to learn and have an awareness of their own strengths and weaknesses:

> *"Somebody who's interested in learning in developing themselves and interested in other people. Somebody who can accept that they might make some mistakes. Somebody who can accept that there may be different ways that people do things."* PA

Insight and Self-awareness

Awareness of strengths and weaknesses requires insight and self-awareness, which can be impaired by brain injury. Therefore, participants felt that it was

important mentors were sufficiently recovered, had insight, and had accepted their own brain injury.

> *"One of the main things that immediately jumped out at me when you asked that question is someone that has reached full acceptance of who they are now post-injury. I think that's the absolute key point."* PC

Lack of insight/self-awareness is connected to disinhibited behaviour, something considered inappropriate for a mentor. Therefore, participants described the importance of ensuring that this is not an issue:

> *"I'd say after the first two years after the person's impact or head injury...then their inhibition has been sorted out."* FG 1

Nurturing Attitude

This concept involves a full consideration of the mentee and a desire to help them to improve and fulfil themselves:

> *"I would want someone that's a little bit kind of maternal or paternal and has an element of wanting to look after wanting to look after that mentee provide the kind of that kind of nurturing. Challenging, but in a gentle way to motivate and encourage."* PC

Relation to framework

These traits are key to the selection and training of mentors to deliver the intervention. They relate to the BCW components of *capability* and *motivation*, both in terms of the capacities of the mentors and also to their ability to facilitate enhanced capability and motivation in their mentee. The 'Who provided' component of the TIDieR checklist is important here, while

‘Tailoring’ is also relevant because a mentor may suit some mentees but not others.

Mode of Delivery

Several participants stated a preference for face-to-face meetings because it facilitates better communication. They pointed out the advantages of being able to respond to body language and eye contact:

> *“I think for any type of communication it's probably best in person. Communication that isn't face-to-face it can be very misunderstood if people can't see body language and read eyes and communicate.”* SD

This facilitates greater rapport and insight into issues that may be unspoken:

> *“You can’t do that over the phone, if somebody is feeling distressed, you look at them in the face and you can tell once you’ve got to know them a bit. Whereas, on the phone there might be a major problem because you’re not going to be able to see.”* FG 2

However, the advantages of remote forms of communication were also noted, such as immediacy and convenience:

> *“Most people like the immediacy of digital.”* SA

> *“I think Skype’s really good and really like undervalued. It’s an immediate way to keep in touch if they are confident using technology.”* SB

It was also considered important to be able to contact the mentor occasionally between scheduled meetings when questions arose, or the mentee needed reassurance:

"I would think that I would want I would want my mentor to be available via email or text or something if I'm having a moment where I don't understand, so I would want it to extend not just to meet this person once a week." PC

The choice of venues for face-to-face meetings was generally thought to be a matter of individual preference. Some thought meeting in a mentee's home would be convenient and comfortable for the mentee:

"I would highly recommend in private and where the patient feels secure. So their place of residence I think." SG

However, some participants pointed out that neutral, community venues would be preferable to meeting in a person's home, both for safety and as a means of getting people out of the house and doing things:

"I think it should be neutral, depending on the mobility issues, I think a neutral venue would be good I would think and it's a good, it's safe, there's people around them and there's no safety issues." SI

The venue and activities would then depend on the mentee's individual preferences and restrictions:

"It depends (pause) on what sort of physical problems a person has as well as I suppose sort of how mobile they are, but for me I think I would prefer it in a neutral venue such as a pub or coffee shop." SB

"Individual choice really, what you're comfortable with and what's appropriate. I wouldn't want them initially at my house. I'd rather choose a café or go for a walk or even here somewhere neutral." FG 2

Relation to framework

This topic is key to the TIDieR elements of 'How?' and 'Where?'. 'Tailoring' is also relevant because it will be important to consider the requirements and capabilities of each individual mentee. It also relates to the BCW component of *opportunity*, because making sure that the mode and location are convenient and enjoyable is key to facilitating engagement with the intervention.

Activities

Most participants felt that dangerous activities should be avoided for safety reasons, and that the intervention should be kept simple. Activities providing safe physical exercise were suggested:

> *"Activities like walking or going to the gym."* SB

Some participants would have liked a mentor to help them return to specific activities they enjoy. This may be something that they lack other forms of support to help them with:

> *"I would love someone that can swim. I miss swimming. I like swimming. These people [carers/support workers] come to my house now but they don't really want to swim."* FG 1

Practical activities, such as helping to make applications for benefits and referrals to Headway, were considered excellent uses of mentoring sessions:

> *"Someone to talk to and someone to help you get the information and forms and help you fill it out. Get them sent off to get you into places like this (Headway)."* FG 2

One of the professional interviewees, who has experience running a peer mentoring intervention, highlighted that pairs do not have to do all the activities in meetings. Instead, a mentor can help the mentee to research how to do something they are interested in:

> *"He was able to think together with the stroke survivor and get him to problem solve, supported him in the problem solving. So it wasn't that he was there pressing the buttons in the computer with him, they would just discuss how to do the digital photographs."* PG

Relation to framework

The activities for mentoring sessions are important for the TIDieR element of 'How', because it involves the content of the intervention, 'Why', because the rationale for the intervention influences the activities, and 'Tailoring', because the activities must be appropriate for both mentee and mentor. The topic also pertains to the 'Activities' and 'Participation' components of the ICF and to aspects of *capability*, *opportunity*, and *motivation* from the BCW.

Risk, Safety, and Logistical Issues

Neutral, public venues were discussed in terms of maximising the safety of participants:

> *"I suppose if you were going into somebody's home and they're really a stranger to you aren't they…you'd have to sort of be quite careful; I think that would be quite worrying unless you were meeting somewhere neutral like a coffee shop."* SB

Some participants were concerned that mentees might become dependent and over-reliant on the mentor:

> *"I think for some people they may become a bit reliant or sort of over friendly with the peer supporter and I think it might be a difficult relationship to break off."* SB

Another concern would be the danger of mentors giving incorrect information or advice. Providing proper training was considered to be extremely important to counteract this risk:

> *"I think if the peer mentors weren't sort of trained in the basics and keeping up to date with the latest statistics and things like that for stroke it's very easy to give the wrong information so you would have to be quite careful about that."* SB

Concerns also came from the idea that mentors could give unrealistic or negative expectations of recovery, either because they have made good recoveries or have severe disabilities:

> *"Oh wow, I want to be just like that without the realization that it takes years to get there. It's unrealistic expectations that scares me, trying to manage expectations."* PC

Professional interviewees were concerned about putting unwelcome pressure on mentors. They felt that mentors might dwell on the dangers and feel overwhelmed by the responsibility:

> *"Maybe they could feel pressure associated with that. And are they doing the right thing? Are they saying the right thing? Pressure to attend the service, even when they might not feel quite up to it?"* PC

One professional stated that these concerns might make them worry about referring people to a mentoring service and letting them meet unsupervised:

> *"My worry is that I'm putting a service user into a situation where their mentor could have a bad day; make a decision that isn't in their best interests and I suppose that's where my biggest worry is...not having enough control over it. Which actually that's probably just me being a control freak."* PC

To mitigate the risks for participants it was considered essential that robust support mechanisms are put in place. Supervisions and debriefs were cited as being important:

> *"I think if you had somebody who was sort of managing them, I guess they would be volunteers but you could do it over skype or something like that just to keep in touch, and also let them offload. If they have difficult situations to deal with I think that's quite important".* SB

The healthcare professionals placed great importance on the thorough screening, selection, and training of mentors:

> *"I think the only way you can do that properly is by being careful about your recruitment of mentors and the training and support of them so that you are closely monitoring those exchanges and making sure that everybody's got what they need."* PA

A lone worker procedure, in which participants report to a professional when going to and from meetings, was frequently discussed:

> *"It's really important…making sure that if you've not rung back within a certain time that there's a procedure that they go through to start ringing you and if they can't get hold of you then they ring your line manager."* PE

Relation to framework

The topics discussed here are vital considerations for the safe delivery of the intervention and for providing reassurance and confidence for participants, carers, and professionals who are asked to refer clients. They pertain widely to all the TIDieR elements, being important for all aspects of intervention design, as well as to the *opportunity* component of the BCW.

Mentor Training

Topics said to be important for training included the effects of brain injury and where to find sources of information:

> *"I think they need basic information on stroke and some sort of further helplines and maybe local information."* SB

Training on appropriate behaviour and boundaries was considered important:

> *"I think they need training on boundaries definitely and maybe even some sort of practice sessions so you can see how they sort of relate to other people…I think the physical contact is an important one because not everybody is very comfortable with that…and people sort of like their own space don't they, that's really important."* SB

Safeguarding the welfare of the mentee was cited as being of particular importance. This involves training mentors to identify potential problems in a mentee's life:

> *"It's important that they're taught about safeguarding and hate and mate crime and the signs to look out for–neglect, self-neglect–all of those things I think need to be encompassed."* PC

Experience of previous mentoring research has highlighted the importance of mentors understanding themselves, their role, their strengths and weaknesses, and how they can improve:

> *"They did a lot of performance profiling...thinking about their qualities and then comparing those with the qualities they thought a peer coach should have. They could then identify which of those qualities they needed to work on."* PG

It is also important that training is not too complicated or overwhelming and should be deliverable by non-experts:

> *"It's going to have to be something that is okay for the lay public to deliver and does not have to be some sort of superduper psychology thing. It should be relatively simple."* PG

<u>Relation to framework</u>

Training is essential to meet the requirements of the 'Who provided?' element of the TIDieR checklist and to ensure mentors have the characteristics identified earlier, can deliver the required mechanisms, and help mentees to achieve the desired outcomes. It is also relevant to all the other components of

the TIDieR checklist, and to the *capability* and *motivation* of mentors and their capacity to enhance these elements in a mentee.

How Long after Mentee's Injury?

Some participants felt the intervention should start as early as possible, just before discharge home:

> *"I would have loved to have visits in the hospital. I was in for eight months so I would have loved someone to come and sit on my bed and say 'look you know this is where you are at the moment and I was there four years ago'."* SI

Returning home was said to be a critical phase of recovery, when mentoring could be particularly valuable:

> *"I'd say towards going home time towards discharge time because that's terrifying when you go home and when the reality sort of sets in."* SI

> *"I think when you get discharged from hospital or rehab you're sometimes in, a very lonely place when you first get home and I think you could do with some support then really."* SB

Other participants said that they would not have been ready for mentoring until much later:

> *"I think for me it was probably about a year, a year and a half, where I was kind of like, I know something's wrong, I need a bit of attention, I need to speak to someone about this, I need support."* BD

> *"The cognitive side of things is quite often, much further down. Because a lot of those cognitive problems don't surface until normal life starts again. That can be a danger if you introduce a mentor too early."* PC

Relation to framework

This topic relates to the *impairment* component of the ICF, in that it is concerned with where a mentee is on their recovery journey, how ready they are for a mentor, and how much they will benefit. It also relates directly to the *capability* component of the BCW.

Duration of Service/Number of Meetings

Considerations of individual differences also applied to how long peer mentoring should last and how many meetings people would need. Flexibility was said to be important:

> *"Sometimes you can do it and give loads and then you might have six months where you've got to step back, so there's got to be some flexibility in it."* SA

It was widely agreed that several meetings would be required for mentoring to be effective, at least three according to this interviewee:

> "*I would say [yeah] at least at least three I think it takes you, I think people can be quite anxious and the first the first meeting might be a little a little fraught at first because some people might be a little bit anxious about what they're supposed to do, and then the next time*

you're a little bit more relaxed and let's say the third time you've got your head around it." SI

Many people felt that mentoring should not go on too long, as there is a risk of developing overdependence, or losing focus:

"The peer coaches did say that they liked the fact that there was a limit because again, they were worried about the dependency thing. And it was nice for them because you didn't want it to drag on too long and people to lose interest and lose the purpose." PG

Frequency of Meetings

While it was felt that there should be flexibility and adaptability to individual preferences, regular meetings not too far apart were preferred:

"I think it can be tailored but I think generally a regular meeting to build rapport and start working on something is useful." PA

Duration of Meetings

Participants felt it was important that meetings do not last too long in order to avoid mentees becoming fatigued:

"When you've had a brain injury you have to manage your fatigue so it might be that they get tired, don't want to chat for too long, so you have to bear in mind their circumstances." SF

The duration of meetings would depend on the activities:

"If they're doing an activity then you do the activity for however long it takes. But if it's just for a basic chat or initially just keep it short, maybe 45 minutes at most." FG 2

Relation to framework

These topics are primarily concerned with the 'When' and 'How much" components of the TIDieR checklist. A primary consideration is the optimum 'dose' for the intervention to be effective without being too onerous or difficult to engage with. Therefore, the subjects also concern the *opportunity* component of the BCW.

Matching Criteria

Mutual interests were said to be an important consideration when matching mentors to mentees:

"If everything else matches as well when they both have an interest in crafts then perhaps we can set them up going to a craft class." PC

Personal rapport was cited as important for the success of a partnership:

"I have experienced many times how not having the same priorities, likes, and ways of doing things brings a lot of unnecessary stress to the equation." SG

Living close together was said to be an important consideration, for convenience, practicality, and the local knowledge of the mentor:

"I think it's useful to have somebody local because then they know about local services and hospitals and things like that." SB

There were different opinions regarding the importance of a mentor having the same type of injury as the mentee. To some, this was very important:

> *"I think I would relate better to someone who's had a stroke or something very similar to me."* SB

While others did not think it mattered and that other factors were more important:

> *"I don't think they need to have had a stroke or know anything about strokes. I think empathy and understanding of the situation are enough."* SG

There were also contrasting opinions regarding the importance of matching for gender and age. Some participants thought that, potentially, there could be a risk of sexual relationships or inappropriate behaviour if men and women were partnered:

> *"I think just to be on the safe side I'd say put two men together and two ladies together."* FG 2

Some said that people of a similar age would be more likely to have things in common and more potential to build rapport, whereas people from different age groups would have very different interests, priorities, and viewpoints:

> *"I think you need to be the same sort of age range; I mean for example I find it more difficult helping people who are sort of 75 plus."* SA

However, many participants thought that differences in gender and age did not matter, and that people often have rapport with people who are very different:

> *"I don't think age, gender or things like race, ethnicity, etc, matter."* FG 2

> *"I think you still have that connection with somebody no matter what sort of background they come from or [age, gender], ethnicity or whatever."* SB

It was considered important that multiple factors are considered in the matching process, with partnerships based on familiarity and understanding of the people involved. This would require the person operating the project to get to know participants well:

> *"I think it needs to be much more personal because people have such individually specific, huge barriers, people's difficulties after brain injury and such subtle changes of personality and communication skills and everything else, that I just think it needs to be done by someone that knows them both very well."* PC

Relation to framework

The matching of pairs is a key consideration of the 'Who provided' TIDieR component. 'Tailoring' is also important because it is important that the mentor is suitable for the mentee.

Context of Delivery

Participants considered the strength of peer mentoring to be its experiential, non-clinical perspective. They said that it should be separate from clinical rehabilitation services in its delivery:

> *"I think that it should be separate because it should not feel like it is coming from the medical side but more like a friend someone you can trust. It should be monitored but more in social way...It should feel more personal and not medical."* SG

However, they also acknowledged the importance of a safety net for participants. Therefore, professional supervision and oversight was considered essential:

> *"I think there should be people overseeing it from the mentor's point of view as well as the stroke survivor, just to be able to check that everybody is safe."* SI

Support would also be useful to help people with organisation and scheduling:

> *"I think it would need to have professionals to oversee it, I think there has to be someone to manage time and schedules...to organise transportation and venues."* SD

It was suggested that peer mentoring could be integrated with rehabilitation services as part of transition to home and independent living:

> *"I think it should be part of rehabilitation coming towards the end when it's time to be coming home…around that time just pre-discharge I think alongside the physios and OTs."* SI

<u>Relation to framework</u>

This topic relates to the 'Who provided' TIDieR component, but in a broader way than considerations of mentor eligibility. It is an important consideration

for many aspects of the delivery of mentoring, which will be developed in the discussion section.

3.6 Qualitative Themes Mapped to ICF and BCW

The findings presented in this chapter can be mapped to the analytical frameworks of the ICF and BCW to provide a picture of how the mechanisms of a peer mentoring intervention can influence functioning and behaviour. This is presented in Table 3.6.

Table 3.6. Qualitative themes in relation to ICF and BCW.

Theme	ICF Components				BCW Components		
	Pathology	Impairment	Activities	Participation	Capability	Opportunity	Motivation
Key attributes of peer mentoring						●	
How peer mentoring helps		●	●	●	●		●
Outcomes of peer mentoring		●	●	●	●		●
Characteristics of a good mentor					●		●
Mode of delivery						●	
Activities			●	●	●	●	●
Risk, safety and logistical issues						●	
Mentor training					●	●	●
When – how long after injury		●			●		
Duration of service / number of meetings						●	
Frequency						●	
Duration of meetings						●	
Matching criteria					●		
Context of delivery							

The table shows that the overall themes map to each element of the ICF and BCW other than ‘Pathology’. This shows that, while mentoring cannot change

the pathological nature of brain injury, it can influence the other aspects of an individual's behaviour and participation. All the themes map to at least one component of the BCW, showing that mentoring can enhance capability, increase motivation, and provide opportunity. The mechanisms of mentoring ('How peer mentoring helps') and the outcomes influence the manifestation of impairment, the impact of the impairment on activities, and the impact of activity limitation on the person's participation in society.

The framework of the topic guides has allowed me to identify all the required elements of the intervention design, according to the TIDieR checklist. Table 3.7 illustrates the coverage of these elements.

Table 3.7. Qualitative themes in relation to TIDieR.

Topic	**TIDieR components**						
	Why	**What**	**Who provided**	**How**	**Where**	**When and how much**	**Tailoring**
Key attributes of peer mentoring	●	●	●	●	●	●	●
How peer mentoring helps	●	●					●
Outcomes of peer mentoring	●	●		●			●
Characteristics of a good mentor			●				●
Mode of delivery				●	●		●
Activities	●	●					●
Risk, safety and logistical issues		●	●	●	●	●	●
Mentor training	●	●	●	●	●	●	●
When – how long after injury						●	●

Topic	TIDieR components						
	Why	What	Who provided	How	Where	When and how much	Tailoring
Duration of service / number of meetings						•	•
Frequency						•	•
Duration of meetings						•	•
Matching criteria			•				•
Context of delivery			•				

This has allowed me to design a prototype intervention described using the TIDieR items, as presented in Chapter Four.

3.7 Discussion

The aims of the work presented in this chapter were to engage with representatives of the target populations (survivors, carers, and professionals) and find out their answers to the following key questions: Is peer mentoring needed? What should peer mentoring aim to do? How should it do it? How do we find and keep mentors and mentees? These aims were in line with the MRC guidelines for developing and evaluating complex interventions (Skivington et al., 2021). In order to provide a framework with which to analyse the data and base the conclusions, I employed the ICF (to show how mentoring can mitigate the impact of disability on impairment, activities and participation), the behaviour change wheel (to show how mentoring can influence behaviour by modifying capability, opportunity, and motivation), and the TIDieR framework

(to show how the findings fit into the essential components of intervention design).

The Patient and Public Involvement and Engagement (PPIE) showed that the main attributes of peer mentoring are the lived experience of the mentor and adaptability to the needs of the individual mentee, which can lead to a broad range of important outcomes. Enjoyment and convenience were considered important, while mentoring could be beneficial for self-confidence, mood, and participation. These factors are key when designing the intervention. It is important to always consider exploiting the adaptability of mentoring for individual needs. Ensuring that it is as enjoyable and convenient as possible are key to retaining participant involvement as well as maximising the effectiveness of the intervention. Outcomes such as reducing depression, stress, and anxiety can be side benefits of other goals, and therefore can be assessed quantitatively without specifically aiming to target them. Participation is something that can be targetted in either an overt way, by encouraging engagement in specific activities, or simply by participants going out and meeting with each other.

The interviews and focus groups showed that, most importantly, people thought peer mentoring would have benefitted themselves or others with injury. They also felt that it should be safe and simple and that the most important elements are the sharing of experiences, providing empathy and understanding, encouragement, reassurance, and information. However, safety was a key consideration, which corroborates the findings from the PPIE strand regarding risk, safety issues, and the embedding of mentoring with professional services. Having a professional to report concerns to and to ensure participants

got to and from meetings safely would provide reassurance. However, this should be kept simple and unobtrusive in terms of the mentoring meetings themselves.

The qualitative findings corroborated those of the PPIE segment regarding the key outcomes that peer mentoring should try to achieve. These should be focussed on the needs of the individual and can be low-key and simple if required. Improved mood and confidence are important side benefits of providing a friendly, understanding person to share experiences and do things with. Enhancing participation was again considered to be important. The mentor provides company and enables the person to get out, they can also introduce them to others or provide strategies that help them to participate more. However, goals and activities should be simple and not too ambitious or complex. Participants talked about activities such as meeting for coffee and going for a walk, rather than discussing complex, difficult hobbies, but the key factor is that outcomes are focussed on the individual and that they have a mentor able to meet their requirements. Sharing coping strategies is another important mechanism by which the mentor can help with participation and other aspects of daily life. Strategies can include ways of facilitating activities and methods of dealing with day-to-day tasks in order to make time available for enjoyable things, thereby enhancing quality of life.

Participants in all groups, including healthcare providers, recognised that the shared experience of a brain injury survivor can help in ways that no professional, friend or family member can. There is a credibility and respect that cannot be replicated with other support services. Mentees can also feel comfortable sharing difficulties and concerns with a mentor that they might not

be able to discuss with family of friends for fear of worrying them, or through embarrassment. Talking to someone who is neutral offers freedom and confidence to be honest. The characteristics of mentors suggested by the interviews and focus groups largely corroborated the findings from the PPIE work and from previous studies (Hibbard et al., 2002; Struchen et al., 2011; Hanks et al., 2012; Coles and Snow, 2011; Fraas and Bellerose, 2010). These could be summarised under the categories of positivity, empathy, realism, friendliness and trustworthiness (Gainforth et al., 2019). Experience of living with the condition and adapting successfully are important and mentors should be motivated, organised, knowledgeable, and have good insight and social skills. Most importantly they should be good listeners. These are important considerations when recruiting and training mentors.

It was clear that face-to-face delivery was considered preferable where possible because it offers the key advantage of going out, meeting up and doing things, which were considered important aims of the intervention. Other forms of contact, such as telephone chats and email, have been used in previous studies with some success (Hibbard et al., 2002; Hanks et al., 2012) and the findings here suggested that people would be happy to use these to compliment face-to-face support or when meeting in-person is not possible. Telephone and email offer the advantages of convenience. However, clear communication is not as easy because of the absence of body language and eye contact, which are considered particularly important for people with cognitive or communication problems.

Participants had slightly differing views on the ideal number of meetings, length of meetings, and their frequency, but it was not considered necessary to

be overly prescriptive about these factors. In designing the intervention for this study, the time requirements of the PhD are important, and participants understood this, but there should be enough meetings to be effective. For example, meeting once was considered not to give time to establish rapport and work on issues. For similar reasons, the meetings should not be too infrequent or irregular. Meetings also should not last too long because they could become tiring. These factors were carefully considered in the final design of the intervention, which will consist of six one-hour meetings in the community, with flexibility for activities or trips.

It was generally agreed that mentoring should not be provided too early (before a survivor has sufficient awareness of the effects of their injury) but should be provided before they lose social contacts or lose interest in activities. Previous studies have recruited mentees at a variety of stages of recovery and their aims corresponded to this. For example, some studies have provided visitors in hospital (Moreci, 1996; Kessler et al., 2014), which involves focussing on learning about the injury, learning about rehabilitation, and the transition home. Other projects have helped people who are living in the community, and tended to focus on everyday issues and social participation (Struchen et al., 2011; Hanks et al., 2012).

The aims of this study, and the practicalities of recruitment, have been considered when establishing the criteria for mentee eligibility and it was required for ethical permission to recruit mentees from rehabilitation services, rather than by self-referral. Therefore, it was initially decided to recruit people within six months of discharge from hospital, in order to examine the

feasibility of delivering mentoring in the community to people in the early stages of recovery who were considered ready by their rehabilitation team.

The risk and safety concerns were important considerations for the design of all aspects of the intervention, and participants emphasised the importance of carefully considering the venues, activities and content of discussions in meetings. Previous studies have also provided relevant information to consider (Kolakowsky-Hayner et al., 2012; Hanks et al., 2012; Struchen et al., 2011), although it is important to note that no published studies have reported adverse events and it is important not to be overly cautious. The results showed that it is important to provide reassurance to mentors and to maintain close communication with them, discuss how meetings have been going, and operate a lone working policy, in which participants report to the researcher before and after meetings. Thorough screening, selection, and training of mentors was essential to all participants and several suggestions were incorporated into the design of the mentor training for the intervention. Professional interviewees and PPIE delegates particularly emphasised risk mitigation and mentor screening, which indicates that the recruitment of mentees from professional services may depend on them being reassured that there are no risks to their patients.

Matching criteria were difficult to define. For example, while many felt that age and gender were irrelevant, others thought them important. Similarly, some people thought that having a mentor with a similar type of injury would be advantageous, while others felt that it did not matter. Most previous studies have investigated mentees and mentors with the same type of injury (strokes or TBIs), so this study breaks new ground in this area and the matching criteria

require careful consideration. The importance of mutual interests and personal rapport are clear from the qualitative findings, but when participants have never met these are difficult to account for.

Mapping the findings to the ICF and BCW components shows that the different elements of mentoring are clearly linked to each element except the ICF component of 'Pathology'. This is because mentoring cannot change the injury itself. However, well delivered mentoring is shown to influence the impairment level experienced by a mentee, the impact this has on their usual activities, and the subsequent limitations on participation in society. The mechanisms, outcomes, and elements of a successful peer mentoring intervention, such as sharing experiences, providing encouragement, achieving personal goals, and enhancing confidence can be mapped onto all these components.

The range of factors identified also map closely to the BCW components of *capability*, in that they improve the skills and abilities of mentees, *opportunity*, by facilitating participation in activities, and *motivation*, by providing the incentive needed to get out and do things. Some of the themes identified are specific to one or two of these elements, while others cover a broad spectrum. Designing an intervention that incorporates all the topics as comprehensively as possible should create a snowball effect, where facilitating some areas creates improvements in others, hopefully manifesting in a positive impact across the person's life. The map of the TIDieR elements indicates a comprehensive coverage of the necessary elements of the intervention by the topics raised in this study. While it is impossible to design the perfect intervention of this kind, and many decisions need to be made which have no

right answers, the study presented in this chapter has allowed for the design of the project described in the following chapter.

A strength of this study was the use of different methodologies, including PPIE group workshops, qualitative interviews, and qualitative focus groups. This allowed me to gather a wealth of rich data by exploring elements of each research question in detail, concentrating on the areas of interest and expertise for each type of participant. I was also able to use group environments, such as the PPIE workshops and the qualitative focus groups, to encourage discussion and exchange of ideas, which allowed topics to develop and evolve, whereas one-to-one interviews allowed me to focus entirely on each individual and to explore their opinions in detail. Also, group environments tend to be dominated by certain individuals while others remain silent, so interviews allow every participant to have an equal voice. Another strength of the study was the collaboration with two MSc students in the delivery of the stroke interviews and the ABI focus groups. This provided alternative ideas and voices in the planning, delivery, and analysis of those strands, reduced the risk of bias, and added to the veracity of the interpretation of the results.

The variety of participants was also a major strength. I was able to gather the views of stroke survivors, TBI survivors, carers, and professionals from a variety of relevant backgrounds, including those with experience of running peer mentoring projects. However, the study's main weakness was also in this area. I was unable to recruit many people with ABIs other than stroke or TBI, with just one person with a brain tumour and one with hypoxic injury, who both took part in focus groups. As the proposed intervention will seek to recruit people with different types of ABI, it would have strengthened the results if

there had been broader representation. Different issues may have come to light regarding recovery and adaptation to injury, while there may have been different views on whether mentees and mentors should be matched for the same type of injury. It is conceivable that people with injuries from conditions such as encephalitis or meningitis would prefer mentors with similar injuries and experiences. No previous research has been conducted to explore this, so there is no further evidence to draw from on the topic.

Another weakness was the lack of participants from ethnic minority groups, with only one non-white ABI survivor, one Finn, and one Australian, one carer of Asian origin, and one service provider from Spain. This means that there were almost no representatives of groups known to be at high risk of TBI and stroke and who may have different experiences of medical treatment and recovery to white British people. The participants also tended to be of high educational level and professional backgrounds, with little representation of people with low education or from low-income jobs. It would have strengthened the study considerably if I could have recruited participants who represented a broader spectrum of social backgrounds and experiences of recovery. The TBI survivors were also predominantly male, while the stroke survivors and carers were mainly female. This is not reflective of the proportion of genders within these groups in society, so female TBI survivors, male stroke survivors, and male carers were underrepresented.

This study has provided the information needed to design a peer mentoring intervention. By supplementing what I learned from previous peer mentoring research with the views of a broad range of survivors, carers, and professionals, I have identified many key elements essential to successful implementation.

4 Chapter Four: Intervention Methods

4.1 Chapter Summary

The systematic review, PPIE, qualitative interviews, and focus groups presented in Chapters Two and Three informed the design of a peer mentoring intervention using the elements of TIDieR as a framework. The next stage of the project was to implement and evaluate the intervention, which was the first of its kind to be conducted with ABI survivors in the UK and evaluated under research conditions.

This chapter will begin by describing the aims and objectives of the intervention study and the feasibility questions it attempts to answer. I will then describe the design of the intervention, followed by the details of the methods employed for recruitment, mentor training, matching pairs, mentoring meetings, quantitative assessment and analysis, and qualitative assessment and analysis.

4.2 Aims and Objectives

The overall aim of the intervention study was to pilot the peer mentoring intervention and assess the feasibility of its delivery and of measuring its effects. Therefore, there were two overarching aims and objectives: 1) evaluate feasibility; 2) evaluate the potential for effectiveness. The aims, objectives, research questions, and methods of addressing them are described in Table 4.1.

The feasibility research questions are presented according to the main objectives and guiding questions for a feasibility study, as outlined by Orsmond and Cohn (Orsmond and Cohn, 2015). These aims, objectives, and follow-up questions were developed by Orsmond and Cohn to guide

researchers to design and evaluate feasibility studies, particularly those focusing on social and behavioural interventions which are not RCTs.

There have been several papers outlining key questions and objectives for feasibility studies (Tickle-Degnen, 2013; Thabane et al., 2010; Hagen et al., 2011). Orsmond and Cohn evaluated all these in a review of studies reporting typologies, frameworks, guidance, or questions for directing the development of pilot or feasibility studies and synthesised their findings into an overarching set of objectives and questions. These fit perfectly with the specific PAIRS objectives and with the nature of this study as a social and behavioural intervention which is not a randomised controlled trial. Therefore, they provide a perfect framework for presenting the feasibility aims and objectives of the PAIRS intervention study. The feasibility questions also complement the MRC framework for developing and evaluating complex interventions (Skivington et al., 2021).

The five main objectives are 1) evaluation of recruitment capability and resulting sample characteristics; 2) evaluation and refinement of data collection procedures and outcome measures; 3) evaluation of acceptability and suitability of intervention and study procedures; 4) evaluation of resources and ability to manage and implement the study and intervention; 5) preliminary evaluation of participant responses to intervention.

Table 4.1 presents the way these main overarching aims and objectives relate to the specific PAIRS objectives and translate into research questions, the important considerations for evaluation, and the methods of evaluation.

Table 4.1. Aims and objectives of PAIRS study.

Aims	Overarching Objectives	Specific PAIRS Objectives	Research Questions	Evaluation Considerations	Evaluation Methods
Evaluation of feasibility	Evaluation of recruitment capability and resulting sample characteristics.	Recruit potential mentors for training. Recruit up to fifteen trained mentors and fifteen mentees. Recruit up to fifteen carers and fifteen Healthcare Professionals nominated by mentees.	Can we recruit the required numbers of appropriate participants? Are the eligibility criteria appropriate?	Was it possible to recruit via planned recruitment sites? Was it possible to recruit the planned number of each participant group? How long did recruitment take?	Outcomes of ethics application process. Numbers of participants recruited. Attrition rates. Qualitative feedback from participants and recruitment sites.
	Evaluation and refinement of data collection procedures and outcome measures	Administer baseline and post-intervention quantitative measures with mentees, mentors and carers. Conduct qualitative interviews with mentees, mentors, carers and Healthcare Providers after the intervention.	How appropriate are the data collection procedures and outcomes measures for the intended population and purpose of the study?	Were the participants able to complete the measures? Were the data complete and useable? Were the measures appropriate for the population and intervention?	Completion rates of measures.
	Evaluation of acceptability and suitability of the intervention	Deliver two-day mentor training course.	Are the study procedures and intervention suitable for	Was mentor training delivered as planned? Were pairings mutually	Training attendance rates. Training feedback.

Aims	Overarching Objectives	Specific PAIRS Objectives	Research Questions	Evaluation Considerations	Evaluation Methods
	and study procedures	Match pairs and introduce them. Each pair to meet independently six times. Pairs to engage in social and leisure activities together.	and acceptable to participants?	acceptable to participants? Were there the required numbers of meetings between pairs? Did participants attend meetings as arranged? What activities did the pairs engage in? Did participants subjectively benefit from the intervention? Were there any adverse events?	Meeting attendance rates. Attrition rates. Qualitative feedback. Researcher experience of delivering the intervention.
	Evaluation of resources and ability to manage and implement the study and intervention	Deliver and manage the study as a single researcher.	Does the research team have the resources and ability to manage the study and intervention?	What were the time and resource requirements of delivering the intervention?	Researcher experience of delivering the intervention.

Aims	Overarching Objectives	Specific PAIRS Objectives	Research Questions	Evaluation Considerations	Evaluation Methods
Preliminary evaluation of effectiveness	Participation	Evaluate whether there were any changes in social, leisure, or community participation and activities.	Does the intervention show promise of being successful with the intended population?	Was there any change between baseline and post-intervention assessments?	Community Integration Questionnaire Individual Goal Attainment
	Quality of Life	Evaluate whether there were any changes in health-related quality of life.			EuroQol EQ-5D-5L
	Psychological health	Evaluate whether there were any changes in depression, anxiety or stress.			Depression, Anxiety and Stress Scale (DASS-21)
	Hope for the Future	Evaluate whether there were any changes in positivity and optimism towards life in the future.			Herth Hope Index (HHI)
	Carer burden	Evaluate whether there were any changes for carers in the perceived level of burden and they felt due to their responsibilities for their loved one.			Caregiver Burden Scale (CBS)

4.3 TIDieR Design and Logic Model

The previous brain injury peer mentoring studies identified in the systematic review employed a variety of designs and models. Two delivered one-off hospital inpatient visits (Kessler et al., 2014; Moreci, 1996), two employed a set number of one-to-one meetings in the same venue each time (Coles and Snow, 2011; Fraas and Bellerose, 2010), while four provided meetings for survivors living in the community by combinations of face-to-face, telephone and email contacts (Hanks et al., 2012; Hibbard et al., 2002; Kolakowsky-Hayner et al., 2012; Struchen et al., 2011). Only two studies included mentors and mentees with different types of injuries or conditions (Fraas and Bellerose, 2010; Kolakowsky-Hayner et al., 2012), although the Kolakowsky-Hayner et al. study attempted to match TBI survivors to TBI mentors. Only one study specifically targetted the improvement of social and leisure participation (Struchen et al., 2011), although there were limited details regarding activities. All the previous studies identified were conducted in North America.

I devised a peer mentoring intervention which incorporated elements of previous designs, while also differing in important ways. One important way in which this would be a unique study was the inclusion of mentees and mentors with any form of ABI, rather than focusing on TBI or stroke as previous studies have done, e.g., (Struchen et al., 2011; Hanks et al., 2012). The UK context of the intervention also made this unique in terms of brain injury peer mentoring research. The intervention setting was designed to be solely community-based and face-to-face, distinguishing it from the majority of published studies, some of which have allowed remote contacts (Hanks et al., 2012; Struchen et al., 2011; Hibbard et al., 2002), while others have relied on

meetings in hospitals or rehabilitation units (Coles and Snow, 2011; Kessler et al., 2014).

The face-to-face aspect of the intervention also made it important to incorporate two other unique elements: 1) An initial meeting at which I am present to introduce the partners and facilitate a discussion about what both the mentor and mentee would like to do in future meetings, what they would like to achieve, the venue and time options for future meetings, discussion topics relating to the mentees learning goals, and other ways to make the meetings as convenient and enjoyable as possible for both partners; and 2) A lone worker policy involving the mentees and mentors contacting me to confirm that they have arrived at meetings and back at home safely.

Another unique element of this project was a focus on the views of carers and healthcare professionals; two groups whose perspectives on mentoring have never previously been assessed. The potential of peer mentoring for relieving carer burden is of particular importance, because of the huge impact of having a brain injured loved one on the psychological health of carers (O'Callaghan et al., 2011; Chan et al., 2009; Bodley-Scott and Riley, 2015). It was also anticipated that feedback from professionals involved in the care of mentees and in recruitment for the study would provide important information about the strengths and weaknesses of the intervention design, recruitment methods, and impacts on mentees.

Table 4.2 provides a description of the intervention according to the criteria of the TIDieR checklist.

Table 4.2. TIDieR description of PAIRS intervention.

TIDieR Item	Intervention features
Name	Peer mentoring for Acquired brain InjuRy Study (PAIRS)
Why	Provide recent brain injury survivors with someone to talk to who understands their difficulties and can pass on the benefit of their experience. To help them cope with the effects of the injury and participate in enjoyable activities.
What	Mentor training: Mentors attend two training days. Training is delivered via talks, discussions, and slide presentations. Mentors are provided with a booklet of information and resources. Intervention: Pairs have an introductory meeting in the presence of the researcher followed by six meetings as a pair.
Who provides	Mentors are selected based on satisfactory completion of training and demonstration of good listening, motivation, insight, organisational skills, confidence, knowledge of support services, responsibility, positivity, experience with injury, positive adjustment to life with injury, and active lifestyle. They are matched to a mentee based on the judgement of the researcher with regard to criteria including age, gender, geographical location, type of injury, personality, and interests.
How	Meetings are one-to-one and face-to-face.
Where	Meetings take place at community venues, such as coffee shops.
When and how much	Six meetings of approximately one hour, every two weeks for three months.
Tailoring	The discussions and activities are tailored to the interests and needs of each individual mentee. Each also sets personal goals they would like to achieve by the end of the intervention.

Figure 4.1 presents the logic model for the intervention describing the rationale, resources, intervention elements, mechanisms, and intended outputs. The moderating and contextual factors are external elements which will influence the success of the implementation.

Figure 4.1 PAIRS logic model.

Rationale
The Problem: Acquired brain injury (ABI) causes long-term physical, cognitive, emotional, and behavioural problems. Survivors require significant long-term support to adapt to the changes and lead fulfilling lives.

The Solution: One-to-one peer mentoring provides individualised support from someone who understands what it is like to have a brain injury.

Project Title: Peer mentoring for Acquired brain InjuRy Study (PAIRS).



Inputs/resources

Recruitment: Time, travel, materials, and expenses.

Mentor training: Time, facilities, travel, materials and expenses.

Administering questionnaires and interviews: Time, travel and expenses.

Mentoring meetings: Time, travel, materials and expenses.



Implementation/intervention

Mentors attend two training workshops at the University of Nottingham.

Partners introduced by researcher at introductory meeting where venues, schedule, and goals for subsequent meetings are planned.

Pairs meet independently six times over the course of three months at community venues to talk and/or do activities.



Mechanisms

Support from someone who has experienced brain injury.

Going out to meet in the community.

Support specific to individual needs.

Strategies to cope with specific problems.

Target personal goals.

Information about living with a brain injury.

Emotional support.



Outputs/outcomes

Improved social and leisure participation.

Improved productivity.

Reduced isolation.

Improved quality of life.

Improved ability to cope with life.

Increased hope for the future.

Enhanced mood and psychological wellbeing. Enhanced knowledge of brain injury related issues. Improved ability to access information and community resources. Meet personal goals. Friendship. Reduced burden on carers.



Moderating and contextual factors
Recruitment (recruiter engagement; participant interest); Participants' life events influencing ongoing availability; Time available to run PhD project; Suitability of pairings; Resource availability; Governance issues.

The main outcomes which will be assessed are participation, mood, hope for the future, quality of life, and carer burden.

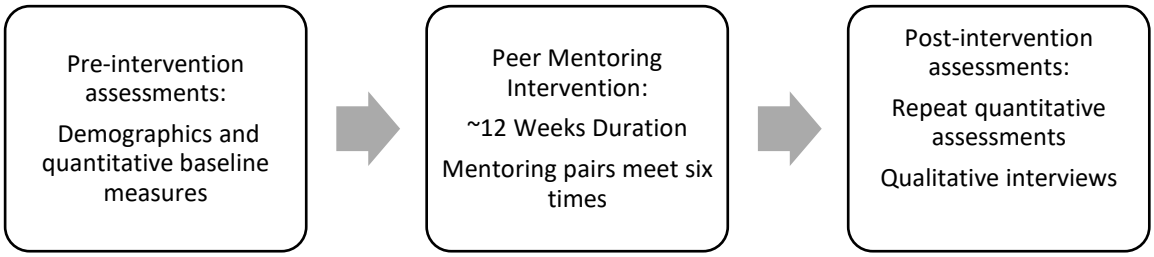
4.4 Ethical Approvals

I applied for the ethical approvals for the intervention study. I conducted all the work independently up to the point of the post-intervention qualitative interviews, for which I was assisted by BP, as described in Section 4.13. Sponsor's approval was received from the University of Nottingham's Research and Innovation Department (ref: 17111). Ethical approval was granted by the East Midlands Nottingham 2 Research Ethics Committee and the Health Research Authority (HRA) (REC reference: 18/EM/0155). Approvals were granted by Research and Development (R&D) and Research and Innovation (R&I) Departments at five NHS Trusts to use their sites as participant identification centres (PICs): Nottingham University Hospitals NHS Trust (NUH); Nottinghamshire Healthcare NHS Foundation Trust; Derby Hospitals NHS Foundation Trust; Derbyshire Community Health Services (DCHS) NHS Foundation Trust; and Sherwood Forest Hospitals NHS Trust.

4.5 Study Design

This was a single-centre, mixed methods, before-and-after study. The assessments were conducted using pre- and post-intervention quantitative measures and post-intervention qualitative interviews. The study design is depicted in Figure 4.2.

Figure 4.2. Study design diagram.



4.6 Sample Size and Rationale

As a small, unpowered, pilot feasibility study, there were no specific requirements for the number of participants. The aim was to recruit up to fifteen mentors and fifteen mentees. Some attrition of participants, particularly mentees, was anticipated, because mentees would be people in the early stages of recovery and learning to cope with their injuries. Therefore, it was likely that their life circumstances would be in a state of flux and several people would be unable to sustain the necessary commitment to complete the project.

The target of fifteen mentees and mentors (the number of mentors had to match the number of mentees) was intended to allow for some attrition, while still providing a sample large enough to provide a choice of mentors and mentees for suitable matching; representation of different ABI types; representation of

different demographic characteristics (e.g., age, gender and ethnic background); statistical analysis robust enough to indicate meaningful changes; and a variety of views for qualitative analysis.

I also intended to recruit one carer and one healthcare professional per mentee. This would provide a sample of up to fifteen carers and fifteen healthcare providers. It was necessary to aim to recruit one for each mentee, but it was anticipated that not all mentees would want to nominate someone, and not all those nominated would be able to participate.

The target total for all four participant groups combined was sixty, with a more realistic total anticipated to be approximately ten mentors, ten mentees, five carers and five healthcare providers.

4.7 Participants

There were four categories of participants in the study: mentees, mentors, carers, and healthcare professionals. The inclusion and exclusion criteria for each participant group are provided in the table below.

Table 4.3. Inclusion and exclusion criteria for participant groups.

Category	Inclusion criteria	Exclusion criteria
Mentees	Aged 18 years or over. Able to give informed written consent. Diagnosed with an acquired brain injury. Living in the community. Discharged from hospital care up to twelve months previously. A service user at a rehabilitation service acting as a participant	Non-English speaking. Lived more than one hour away (or reasonable travelling distance) from the recruiting centre.

Category	Inclusion criteria	Exclusion criteria
	identification centre (PIC) for the project at the time of recruitment. Considered by referring clinicians to have the physical and cognitive capacity to participate.	
Mentors	Aged 18 years or over. Able to give informed written consent. Diagnosed with an acquired brain injury. A minimum of one-year post-discharge from hospital after injury. Living in the community. Reference of suitability from a brain injury professional. Able to complete training satisfactorily and demonstrate suitability for the mentor role	Non-English speaking. Lived more than one hour away (or reasonable travelling distance) from the recruitment centre.
Carers	Aged 18 years or over. Able to give informed consent. Nominated by the mentee participant. A partner, relative, or friend who knew the mentee well and saw them regularly.	Unwilling to participate.
Healthcare providers	Aged 18 years or over. Able to give informed written consent. The primary contact for recruitment at a participant identification centre (PIC).	Unwilling to participate.

4.8 Recruitment

There were slight variations in the recruitment procedures for each group of participants. The following sub-sections explain these procedures. For

examples of recruitment adverts, expression of interest forms, information sheets, and topic guides see Appendices 9–11 and 13.

Mentees

Mentees were recruited from brain injury rehabilitation services at five NHS Trusts in Nottinghamshire and Derbyshire. I discussed the project with the managers of these services, gave presentations to the healthcare teams, and provided participant information sheets, expression of interest forms, and recruitment posters. Members of the healthcare teams informed eligible patients about the project during appointments, then obtained permission from anyone expressing an interest to pass their contact details on to me. I then contacted potential participants by telephone or email to discuss the study.

Mentors

The clinical teams were asked to identify current or former service users they felt would make appropriate mentors (based on the eligibility criteria) and approach them to enquire about their interest and for permission to pass their contact details on to me. The teams were also asked to place mentor recruitment posters in clinical areas.

Mentors were also identified via the brain injury charities Headway, Stroke Association, Different Strokes, Brain Tumour charity, Encephalitis Society, and Meningitis Now. I contacted managers and research leads at these organisations and, following permission, posted adverts on their websites, social media channels, and at local day centres. I also approached brain injured former participants (who had consented to future contact) in studies by the project's primary supervisor. I explained the project to all interested parties and

provided them with participant information sheets. People who self-referred from adverts with the charities were asked to provide contact details of a brain injury rehabilitation professional who had treated them previously and could act as a reference to confirm their suitability.

Potential mentors were invited to a two-part training workshop, which is described in detail in Section 4.9 and Appendix 12. People who completed the training were asked to provide written consent to participate in the project as mentors. In order to mitigate against University liability issues in the event of incidents during mentoring sessions, the mentors were regarded as volunteers with the University, which involved completing a Disclosure and Barring Service (DBS) check of their past police record, receiving a University Volunteering Toolkit and volunteer benefits, such as support from the Volunteering Service and free onsite parking.

Carers

Carers were included in the study to find out whether mentoring helped to relieve some of the burden of caring for the mentee and to gain the carers' perspectives on the mentoring intervention. Mentees were asked to nominate a partner, relative, or friend who knew them well and saw them regularly to participate in the study as a carer. The mentees were asked to discuss the study with the nominated person, provide them with participant information sheets, and confirm that they agreed to being contacted by me. I then discussed the project with the carers and asked them to provide written consent to participate.

Healthcare Providers

Mentees were also asked to nominate a member of their current or former healthcare team (i.e., a recruiter at one of the PICs) to participate in a post-

intervention qualitative interview as a healthcare provider and provide their perspective on the feasibility of the study. As these professionals had already been briefed by me on the project, they simply needed to agree to me contacting them to discuss their participation.

Informed Consent

It was explained to all participants that entry into the study was entirely voluntary and that they could withdraw at any time. Participants were informed that all information they provided would be anonymised, and no identifiable details would appear in any published documents. I explained to all mentors and mentees that I would inform their GP about their involvement in the project, so they would be required to provide me with the name of their GP practice.

Informed consent was obtained from the participants after they had been provided with the participant information sheet and had the opportunity to discuss the project with friends, family, and healthcare workers, and ask me questions. Consent was usually obtained at participants' homes (in the cases of mentors, mentees, and carers), although some mentors completed their consent forms at the training workshop. Healthcare providers were asked for consent at their places of work.

4.9 Mentor Training

The potential mentors were invited by letter and email to attend two training days at the Lakeside Arts Centre, University of Nottingham. This venue was chosen because of its excellent, comfortable facilities, with good access for those with disabilities, close proximity to public transport links and the centre

of town, easy access by car, and free parking. They were provided with directions to the venue and informed that refreshments would be provided and that there would be regular breaks. They were asked to retain receipts or mileage details for any travel costs incurred so that the University could reimburse them. The venue provided audio-visual equipment and an easel, while all writing equipment, paper and pads were provided by my university department. A divisional administrator (PD) was responsible for issuing invitations, booking the venue, and organising catering.

The structure of the training days and embedded sessions was designed by me with input from my primary supervisor (KR) and an occupational therapist colleague (JP), who had expertise in brain injury. She had experience of delivering training for participants in other research projects and assisted me in running the training. The sessions were further developed over a series of practice sessions with colleagues in the Division and a volunteer with a brain injury (JF). JP helped to set up the room, greet participants, hand out materials, write down ideas in group activities, interact with participants, take part in activities, and assist in any other way needed. She also helped me to assess the suitability of the participants for the mentoring role.

The sessions were recorded on a mobile phone voice recorder app and Dictaphone with the participants' consent. Evaluation forms were provided and participants were asked to complete one at the end of the second training day.

For further details about the procedures, content of the training days, and evaluation form items, see Appendix 12.

4.10 Matching Mentors to Mentees

I matched each mentor to a mentee who most closely fit the following criteria:

- Shared interests/hobbies.
- Same gender (male to male; female to female).
- Nearby location (living close to each other).
- Similar effects of brain injury (e.g., experience with fatigue problems, memory problems, organisational problems, etc.).
- Compatibility of the goals both parties set during the initial assessment (e.g., both wanting to go for walks).

I attended the first meetings with each pair to introduce them, explain the mentoring process, agree suitable methods of communication, discuss ideas for activities and venues, and resolve any queries or concerns. I talked privately with each participant afterwards to confirm they wanted to proceed with further meetings. They were given the option of being re-matched with someone else if they wished and if another suitable participant was available.

4.11 Mentoring Meetings

Pairs were asked to meet at a mutually convenient venue six more times over approximately twelve weeks. It was recommended that the meetings were conducted face-to-face. However, it would have been acceptable to talk on the phone or by videocall, on occasion, if face-to-face meetings were difficult to arrange. Mentors and mentees were encouraged to maintain contact with me throughout the study to discuss progress, challenges, queries, and concerns.

The meetings were intended to focus on the following mechanisms: encouraging the mentee to take a positive outlook towards their brain injury;

promoting participation in activities of importance to the mentee; reducing emotional distress and anxiety by sympathetic listening and sharing of experiences; reducing isolation; increasing hope for the future; and boosting confidence and self-esteem. The pairs were encouraged to work towards the aims each partner stated in their baseline assessments and during their introductory meeting.

The duration and location of meetings was partly dependant on the activity planned for each session. If the pair met to talk over coffee, then sessions were intended to last no more than approximately one hour. If they pursued an activity together then the duration would depend on the nature of the activity.

Participants were advised that activities should not involve dangerous or advanced physical pursuits. Acceptable activities included going for a walk, going to the cinema, playing board games, shopping, going for coffee, jogging, etc. Funding was available to cover basic expenses (no specified limit) such as travel, café bills, etc. Participants were provided with expense forms and asked to return them to me after the meetings, along with their receipts.

A lone worker policy was operated, which required mentors and mentees to inform me by text or telephone call at the beginning and end of each mentoring session. Participants were also asked to inform someone they knew (such as someone they live with) about where they were going.

Several further steps were taken to protect participants. As explained earlier, mentors were given official status as University volunteers (although not officially registered in order to protect their anonymity), which required them to undertake a DBS check and also gave them rights to support from the

University if they had any issues. Mentors were also offered a pay-as-you-go mobile phone and University of Nottingham email address to protect their privacy. Mentees were given the option of providing personal contact details to the mentor or, alternatively, using me as a point of contact. Mentees were asked not to contact their mentor outside of the scheduled sessions other than to arrange meetings.

4.12 Quantitative Methods

The measures described below were administered to participants before and after the intervention. The baseline assessments were intended to be conducted as close as possible to the start of the intervention and post-intervention assessments were planned for as soon as possible after the intervention. I anticipated that there would be delays to starting some partnerships, due to the complexities of matching compatible partners, and to the final assessments, due to scheduling for the participants' convenience. Table 4.4 shows the planned schedule of delivery.

Table 4.4. Schedule of assessments.

Measures	**Time (mins)**	**Baseline:** **Up to one month prior to commencement of intervention**	**Peer mentoring intervention** **12 Weeks**	**Post-intervention:** **Up to one month after completion of intervention**
Mentees and mentors				
Community Integration Questionnaire (CIQ)	15	✓		✓
Depression, anxiety and stress scale (DASS–21)	10	✓		✓
EuroQol EQ–5D–3L	5	✓		✓
Herth Hope Index (12-item) (HHI)	5	✓		✓
Mentoring goals	10	✓		✓
Peer mentoring questionnaire	20			✓
Qualitative interview	30–60			✓
Carers				
Caregiver Burden Scale (CBS)	10	✓		✓
Qualitative interview	30–60			✓
Healthcare providers				
Qualitative interview	30–60			✓

Quantitative outcome measures were administered at the participants' homes at baseline and post-intervention via telephone (participants were not required to

return any questionnaires by post). The assessments were completed on paper initially, then written up on Microsoft Word and uploaded to a secure University of Nottingham server. Paper copies were stored in a secure filing cabinet at the University. All data were entered onto SPSS version 24.0 for analysis.

4.12.1 Quantitative Outcome Measures

The following measures were chosen for their relevance to the target outcomes, applicability to brain injury, reliability, validity, usability, and brevity.

Community Integration Questionnaire (CIQ) (Willer et al., 1993)

This measure was chosen to ascertain levels of participation, community integration, and independence. It is a brief and easy to administer questionnaire consisting of fifteen items. The items are divided into three domains: home integration (e.g., meal preparation, housework, and childcare) scored 0–10; social integration (e.g., shopping, visiting friends, and leisure activities) scored 0–12; and productive activity (e.g., employment, school, and volunteering) scored 0–7. A total score of 0–29 is calculated for all the items combined. The measure is scored positively, so the higher the score the better the outcome.

The CIQ has been shown to have excellent validity, reliability, and internal consistency in people with TBI, stroke and other forms of ABI (Willer et al., 1993; Zhang et al., 2002; van Baalen et al., 2006; Kuipers et al., 2004).

EuroQol EQ-5D-5L (Herdman et al., 2011)

This measure was selected to ascertain participants' health-related quality of life. It provides a descriptive system of five domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension requires a

response corresponding to five levels, from one ('No problems'), to five ('Extreme problems'). The responses for each of the five dimensions can be combined to give a five-digit number describing the person's health state. There is an additional Visual Analogue Scale (VAS) on which the person rates their health that day on a scale of 0 ('The worst health you can imagine') to 100 ('The best health you can imagine'). The EQ-5D-5L is a quick and simple measure to use and has been demonstrated to be valid and reliable with the ABI population (Alderman et al., 2001; Golicki et al., 2015; Pinto et al., 2011).

Depression, Anxiety and Stress Scale (DASS-21) (Lovibond and Lovibond, 1995)

This scale was chosen to measure levels of depression, anxiety, and stress. It is a combined set of three scales with items from each scale interspersed within one questionnaire. Each item is measured on a four-point Likert scale from zero ('Did not apply to me at all') to three ('Applied to me very much or most of the time'). The score for each item is doubled and the items on each scale are added together for the total scores of each. Scores can be categorised into 'Normal', 'Mild', 'Moderate', 'Severe', and 'Very severe'. The DASS-21 has been widely shown to be valid and reliable with non-clinical populations (Osman et al., 2012) and has also been validated with a TBI population (Dahm et al., 2013; Randall et al., 2017). It is quick to complete and places a minimal burden on participants.

Herth Hope Index (HHI) (Herth, 1992)

The Herth Hope Index (HHI) was chosen to provide a measure of hope for the future, which studies have shown to be an important coping mechanism after difficult events (Hunsaker et al., 2016). The HHI is a brief, 12-item version of

the Herth Hope Scale (Herth, 1991), using a four-point Likert scale (one: Never applies to me; two: Seldom applies to me; three: Sometimes applies to me; four: Often applies to me) for each item to give total scores from 12 to 48, with higher scores corresponding to higher levels of hope. The HHI has been shown to be valid and reliable in psychometric studies with a variety of populations (Herth, 1992; Phillips-Salimi et al., 2007; Katerndahl et al., 2002), although I am unaware of any previous studies with ABI survivors.

Caregiver Burden Scale (CBS) (Zarit et al., 1980)

The Caregiver Burden Scale (CBS) was chosen to assess the level of burden on carers of mentees. The CBS is a 22-item questionnaire which requires the carer to endorse statements on a five-point Likert scale. Responses for each item range from zero ('Never') to four ('Nearly always'). The final item asks the carer to rate their overall level of burden from zero ('No burden at all') to four ('Extreme burden'). Overall scores range from 0 to 88, with higher scores showing higher levels of burden. The scores can be categorised by severity of burden on the following levels: 0–20 ('No or minimal burden'), 21–40 ('Mild to moderate burden'), 41–60 ('Moderate to severe burden'), and 61–88 ('Severe burden'). Studies have demonstrated good reliability and validity (Hébert et al., 2000) and the CBS has been used frequently in studies of carers for stroke, TBI, and other ABI survivors (Caplan et al., 2015; Elmståhl et al., 1996; Harding et al., 2015; Siegert et al., 2010).

Peer Mentoring Questionnaire (PMQ) (Hibbard et al., 2002)

This was chosen to assess the impact of mentoring on mentees and their satisfaction with the design of the intervention. It was adapted from an original

questionnaire designed for the Traumatic Brain Injury Mentoring Partnership Programme (TBI–MPP) operated in New York State and New Jersey, USA, in the early 2000s. There are 29 items divided into two parts. Part One consists of six categories: 'Empowerment and quality of life'; 'Mood'; 'Skills and knowledge'; 'Social support'; 'Practical issues'; 'Emotional adjustment'; and 'Satisfaction with the programme'. The items in Part One required responses to the question 'Please indicate how much you feel the peer mentoring programme helped (you/the mentee) in the following areas…'. Responses were from a choice of 'No help', 'Some help', Great deal of help', and 'Don't know'. These response options are taken from the version of the PMQ used by Hanks et al. (Hanks et al., 2012) and I also added 'Don't know' added as an additional option.

The PMQ has not been validated. However, its usefulness and specificity to the topic meant that it was a valuable tool to employ for this study. Despite not having its reliability and validity evaluated, the PMQ has a solid scientific basis. It was developed by Hibbard et al. for use in a similar peer mentoring project, previously reported in Chapter Two (Hibbard et al., 2002). The authors reported that a panel of TBI experts selected and adapted the questions from four existing, validated measures: the Questionnaire on Resources and Stress–Short Form (QRS-SF) (Allen et al., 1994), the Frequency of Family Coping Behaviours (FCB) (Kosciulek, 1994), the Social Support Questionnaire–Short Form (SSQ–SR) (Pierce et al., 1986; Sarason et al., 1983), and the Empowerment Scale (Rogers et al., 1997). Hibbard et al. stated that selection criteria for the items included question clarity and relevance to the mentoring programme. Part Two was related to 'Satisfaction with the programme' and

consisted of these four items with a choice of four responses to each: ‘Length of mentoring sessions’ (Too short; Too long; Just right; Don’t know); ‘Number of times met with mentor/mentee’ (Not often enough; Too often; Just right; Don’t know); ‘How satisfied with mentor’ (Not; Somewhat; Very; Don’t know); ‘How comfortable with mentor/mentee’ (Not; Somewhat; Very; Don’t know).

Individualised Goals for Mentors and Mentees

All mentees and mentors were asked to name up to four goals that they would like to achieve from their involvement in the project. These were set as part of the baseline assessments. The goals were not intended to be quantifiable or measured on a scale. They could include aims such as ‘meeting someone new’ or ‘getting out of the house’. Therefore, no standardised measurement of goal attainment was used. Participants were asked at post-intervention interviews whether they thought they had achieved each goal.

4.12.2 Quantitative Analysis Methods

The baseline and post-intervention scores for all the outcome measures were entered into SPSS Version 24.0 and mean scores, standard deviations, ranges, and changes were calculated for each participant group and for individuals. Paired samples t-tests were conducted to assess the post-intervention changes from baseline. Data were plotted on a histogram to assess normal distribution visually.

4.13 Qualitative Methods

The post-intervention mentor, mentee and carer interviews were conducted by BP, a postgraduate researcher who was also supervised by the project’s chief

investigator (KR). The rationale for an independent researcher conducting the interviews was to encourage participants to speak freely about the project and any negative aspects, without fear of offending me. I conducted the healthcare provider interviews. BP also assisted me with the data analysis in order to provide veracity to the findings by independently identifying themes and collaborating on their refinement.

The interviews were conducted by telephone, audio-recorded, and transcribed verbatim, with all personally identifiable data removed from the transcripts. The audio recordings were stored securely on a University of Nottingham server.

The mentor, mentee, and carer interviews consisted of nine questions divided into three main sub-categories; 'Personal experience of the programme'; 'Programme attributes'; and 'Future implementation'. The healthcare provider interviews consisted of ten questions focusing on experience of peer mentoring services, expectations of peer mentoring, recruitment issues, and implementation issues.

The topic guides and analysis were informed by the theoretical frameworks outlined earlier: the International Framework of Functioning, Disability and Health (ICF) and the behaviour change wheel (BCW). The constructs of these frameworks are shown in Table 4.5.

Table 4.5. Frameworks informing the topic guides and analysis.

Key concepts	**Definition**
International Framework of Functioning, Disability and Health (ICF)	
Functioning	An umbrella term for body functions, body structures, activities, and participation. It denotes the positive or

Key concepts	Definition
	neutral aspects of the interactions between a person's health condition(s) and that individual's contextual factors (environmental and personal factors).
Body functions (e.g., mental functions; sensory functions; voice and speech functions).	The physiological functions of body systems (including psychological functions).
Body structures (e.g., structure of the nervous system; eye, ear and related structures; structures related to movement).	Anatomical parts of the body such as organs, limbs and their components.
Activity	The execution of a task or action by an individual.
Participation (e.g., learning and applying knowledge; general tasks and demands; mobility; self-care; interpersonal interactions and relationships).	Involvement in a life situation.
Disability	An umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between a person's health condition(s) and that individual's contextual factors (environmental and personal factors).
Impairments	Problems in body function and structure, such as significant deviation or loss.
Activity limitations	Difficulties an individual may have in executing activities.
Participation restrictions	Problems an individual may experience with involvement in life situations.
Environmental factors (e.g., products and technology; natural environment; support and relationships; services, systems and policies).	The physical, social and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person's functioning.
Personal factors (e.g., age, gender, personality, education, employment history, interests, attitudes and beliefs).	Factors related to the specific background of an individual's life and living, including features that are not part of a health condition or health states, and which can impact functioning positively or negatively.
Behaviour Change Wheel	

Key concepts	Definition
Capability	An individual's psychological and physical capacity to engage in the activity concerned.
Opportunity	All the factors that lie outside of the individual that make the behaviour possible or prompt it.
Motivation	Internal processes that energise and direct behaviour, not just goals and conscious decision-making. Includes habitual processes and emotional responding, as well as analytical decision-making.

I have followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (Tong et al., 2007).

4.13.1 Qualitative Analysis Methods

Thematic analysis followed the seven-step Framework Method, as defined and described by Gale et al. (Gale et al., 2013). This method was used in the analysis of the PPIE and qualitative study described in Chapter Three and the rationale is presented there on pages 98–99.

The analysis procedure, in accordance with the seven stages of the Framework Method, was as follows:

Step One: Transcription.

The interviews were recorded on a digital voice recorder and the audio files were saved on a university computer on a secure drive. The mentor, mentee, and carer interviews were then sent to an outsourced transcription service. Long pauses, laughter, interruptions, and unclear speech were noted on the transcripts. I listened to the recordings while reading the transcripts, correcting inaccurate transcription, and anonymising by removing identifiable references

to individuals or places. I transcribed the healthcare provider interviews myself using a free online transcription software package called Otter, which is provided by the Otter.ai company (www.otter.ai). The Otter software uses artificial intelligence to provide live speech-to-text transcription. As a free online package, it has a significant cost advantage over expensive professional services. I played recordings of the interviews while simultaneously running the speech-to-text transcription programme online. The programme was prone to errors, so it was necessary to monitor the transcription and pause recording while correcting the errors. Once the transcription was completed on the Otter website, it was saved as a Microsoft Word file.

Step Two: Familiarisation with the interview.

BP and I read each transcript three–four times, listened to the recordings, and made notes of observations and overall impressions.

Step three: Coding.

We independently highlighted sections of the transcripts and added paraphrases, labels, and topic headings to describe what we interpreted as important. The main codes were pre-defined by the topics of the interviews.

Step Four: Developing a working analytical framework.

The qualitative strand was partly deductive, following a general framework based on the ICF and the BCW.

Step Five: Applying the analytical framework.

BP and I independently linked coded sections of the text to the overarching topics and created groups of related sub-topics. We then compared findings and had regular discussions to reach a consensus on the final topics.

Step Six: Charting the data into the framework matrix.

Sections of the transcripts were entered into a matrix on Nvivo 12 and on Excel spreadsheets. The matrix consisted of rows for each participant and columns for each theme and sub-theme. Sections were labelled with notes and ideas for refined themes.

Step Seven: Interpreting the data.

Themes were generated by an iterative process of reviewing and combining topics in the matrix. I produced a series of draft topics and categories, and BP made comments and suggestions. The process was influenced by both the original research objectives and by concepts which emerged inductively. The process was complete when all the concepts and quotes which both researchers identified as important were included within topics and categories which summarised the key findings.

4.14 Data Synthesis Methods

The final stage of analysing the results was to synthesise the information from the different quantitative and qualitative sources. This was achieved by using convergence coding (O'Cathain et al., 2010) and creating a joint display to show where the separate sources of data agreed, disagreed, or provided complimentary information (McCrudden et al., 2021).

5 Chapter Five: Results

5.1 Chapter Summary

This chapter presents the results from the pilot of the intervention study described in Chapter Four. This will begin with a summary of the numbers and demographics of each group of participants. I will then present the results of the study as it progressed, beginning with training the mentors, followed by a summary of the mentoring pairings and the numbers of meetings each had. I will then present the results for each feasibility question the study investigated, followed by the quantitative results comparing before-and-after assessments and qualitative analysis of the post-intervention interviews with participants. The chapter will conclude with a discussion of the results which will lead into a more general discussion of the whole project in Chapter Six.

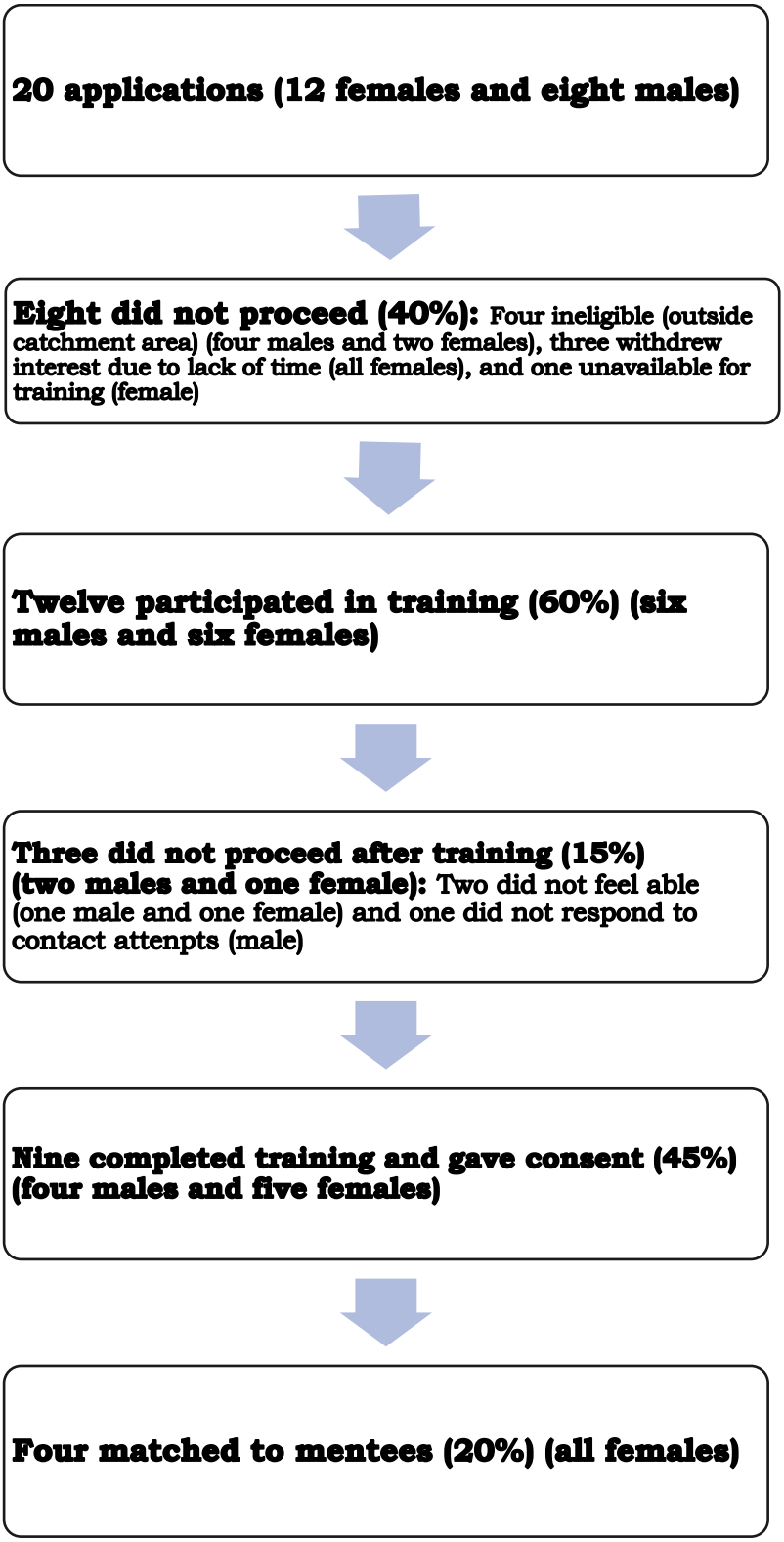
5.2 Study Participants

This section presents the pathway through the recruitment and participation process for each participant category.

Mentors

The recruitment of mentors ran from June 2018 to December 2018. A total of twenty people expressed an interest in being mentors.

Figure 5.1. Mentor recruitment flowchart.



Most prospective mentors were TBI survivors (n = 12). There were also three people with brain tumours, two stroke survivors, two encephalitis survivors, and one person with an anoxic brain injury. They were recruited from these sources:

- Responded to internet advert (n = 9)
- Referred by rehabilitation team (n = 6)
- Participants in previous studies who had consented to contact for other projects (n = 2)
- Referred by brain tumour charity (n = 2)
- Referred by Headway group (n = 1)

Further details of participants at the mentor training days are provided in Section 5.3 and Appendix 12. The demographics of the four people who participated as mentors are provided in Table 5.1.

Table 5.1. Mentor demographics.

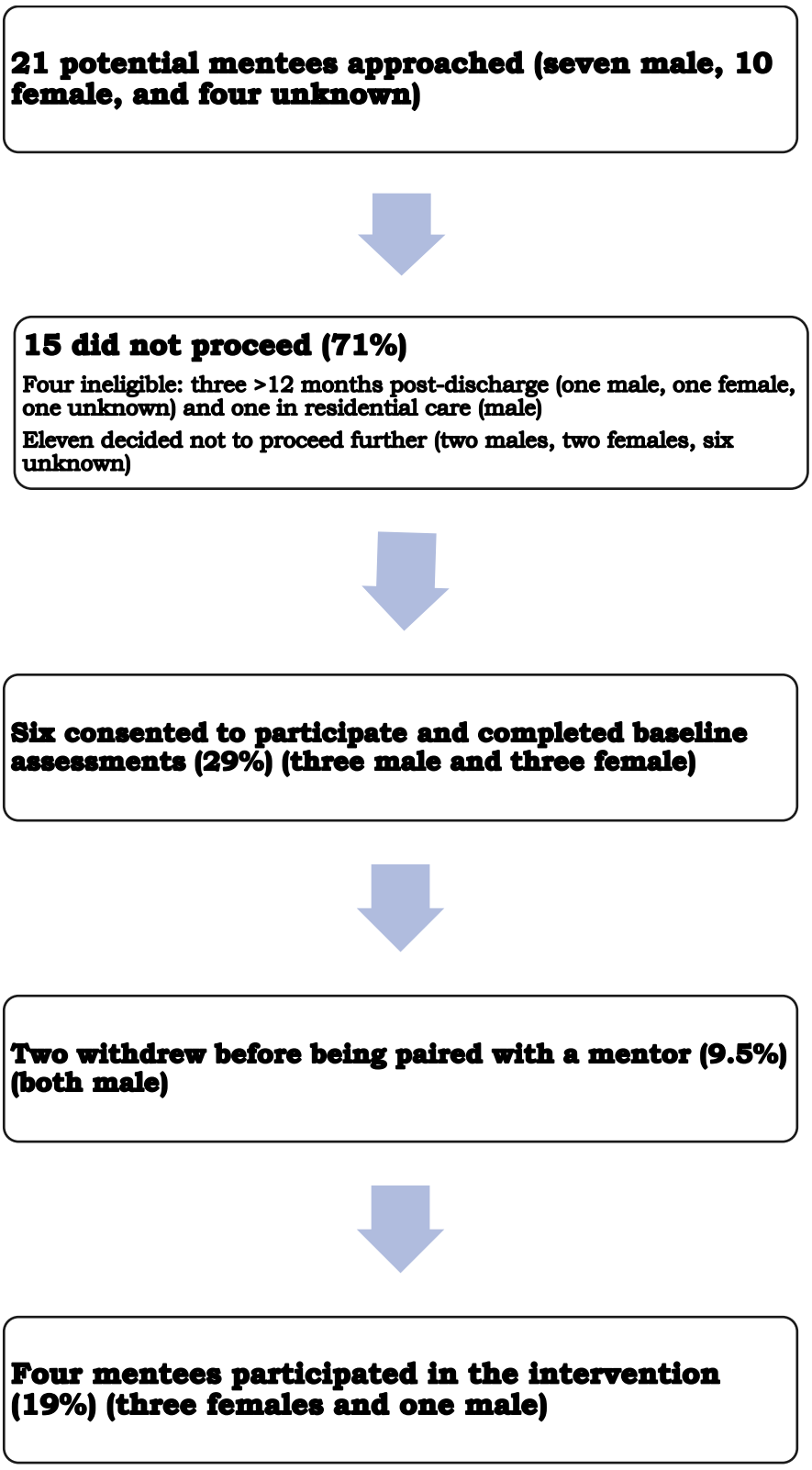
ID	Age	Gender	Ethnicity	Type of injury	Time since injury (months)	Employment status	Education level
Mentor One	30	F	White British	TBI	141	Full-time	GCSE
Mentor Two	40	F	White British	Anoxia	39	Retired due to disability	Degree
Mentor Three	44	F	White British	TBI	254	Part-time self-employed	Degree
Mentor Four	49	F	White British	TBI	54	Part-time	Degree

The age range of the four mentors was 30–49 years (mean = 40.75; SD = 8.06). The time since their injuries ranged from 39 months (3 years, 3 months) to 254 months (21 years, 2 months) (mean = 122 months (10 years, 2 months); SD = 98.82).

Mentees

The recruitment of mentees ran from June 2018 to March 2019. A total of 21 potential mentees were identified by the recruitment sites.

Figure 5.2. Mentee recruitment flowchart.



The majority of potential mentees identified were TBI survivors (n = 12). There were also seven stroke survivors, one encephalitis survivor, and one unknown (details were not disclosed to me by the PIC). Four were ineligible and eleven decided not to proceed further, although reasons for this were only provided by two people. One felt that she was not sufficiently impaired to benefit, and one wanted to be paired with a fellow female stroke survivor, which was not possible. The two who withdrew after providing consent cited changed personal circumstances as reasons.

The demographic details of the four remaining people who participated as mentees are provided in Table 5.2.

Table 5.2. Mentee demographics.

ID	Age	Gender	Ethnicity	Type of injury	Time since injury	Employment status	Education level
Mentee Two	59	F	White British	TBI	12 mos.	Retired	Degree level
Mentee Three	79	F	White British	Stroke	9 mos.	Retired	Higher education qualifications
Mentee Five	51	M	White British	Stroke	5 mos.	On sick leave	GCSE or equivalent
Mentee Six	68	F	White British	Encephalitis	5 mos.	Retired	Professional qualification.

The age range of mentees was 51–79 years (mean = 64.25; SD = 12.04). The time since their injury ranged from 5 to 12 months previously (mean = 7.75 months; SD = 3.40).

Carers

Of the six people who consented to be mentees, four nominated a carer to participate in pre- and post-intervention assessments. All four carers consented and completed the baseline questionnaires. One mentee withdrew, so his carer

played no further part. The remaining three completed post-intervention questionnaires. Two also took part in qualitative interviews, while the other declined to participate. The demographic details of the carer participants are provided in Table 5.3.

Table 5.3. Carer demographics.

ID	Age	Gender	Ethnicity	Weekly hours spent providing care	Employment status	Relationship to injured person
Carer One	52	M	White British	6–8	Full time	Son
Carer Three	54	F	White British	25	Full time	Wife
Carer Four	65	M	White British	None specified	Full time	Husband

The age range of the carers was 52–65 years (mean = 57; SD = 7.0).

Healthcare Providers

Contrary to the original protocol, none of the mentees were able to nominate a healthcare provider as a participant in the project. This was because they all either discontinued using the rehabilitation service soon after enrolment, or the professional they were primarily in contact with changed. Therefore, it was not possible to conduct post-intervention qualitative interviews with professionals who had personal insight into the mentees. However, as an alternative approach, five healthcare providers (HCPs) who were primary contacts for recruitment agreed to participate. This was intended to provide me with insight into their professional opinion of peer mentoring in general, and this project design specifically, and the barriers and facilitators to recruitment. I conducted the interviews by Video Call on Microsoft Teams, which was virtually

unknown at the time of initially planning the project and which provided a particularly useful way of interacting with the interviewees remotely while allowing face-to-face contact and visual communication cues.

The demographic details of the healthcare providers are provided in Table 5.4.

Table 5.4. Healthcare provider demographics.

ID	Age	Gender	Ethnicity	Role	Length of time in role
HCP One	39	Female	White British	Occupational therapist at TBI outpatient rehab service	5 years
HCP Two	39	Male	White British	Physiotherapist and clinical lead at community stroke service	4 years
HCP Three	45	Female	White British	Occupational therapist at neurorehab outpatient service	10 years
HCP Four	55	Female	White British	Assistant rehab practitioner at neurorehab outpatient service	19 years
HCP Five	34	Female	White British	Head injury clinical specialist, occupational therapist and case manager with community brain injury outpatient service	2 years

The age range of healthcare providers was 34–55 years (mean = 42.4; SD = 7.2).

5.3 Mentor Training Results

Participants

Training day one: There were twelve participants, including ten brain injury survivors (five females and five males) and two carers (both female). Training Day Two: There were nine participants (five females and four males, all brain injury survivors). Six participants attended both days (four females and two males).

In total, 12 potential mentors participated over the two training days. One male participant and one female participant stated that they no longer wished to be mentors because they did not feel ready. Another male participant did not respond to further attempts at contact and did not attend the second training day. Nine people completed the training (five females and four males).

For those who could not attend some or all of the training, I sent them the training materials by email and discussed it with them on the telephone. This was not a satisfactory alternative to attending the sessions, but we were able to discuss the main topics and replicate some of the activities/discussions.

All participants actively engaged with the activities and discussions, stated that they enjoyed the training days, and found them extremely useful and effective for preparing them to become mentors. No participants were considered unsuitable candidates, and all would have been considered if there had been more mentees available. One was matched to a mentee who withdrew prior to the commencement of mentoring.

Training Evaluation Forms

Five participants handed in their evaluation forms. The responses to the Likert scale questions were as follows:

1) The sessions were well structured: Strongly agree—4; Agree—1
2) The sessions were enjoyable: Strongly agree—3; Agree—2
3) The training has made me feel well-equipped to be a peer mentor: Strongly agree—4; Agree—1
4) The training covered everything I need to be a peer mentor: Strongly agree—2; Agree—2; Neutral—1

5) The trainer conveyed the topics well: Strongly agree—3; Agree—2

6) The handouts were useful: Strongly agree—3; Agree—2; Neutral—1

Responses to the free text questions included the following:

"I found all topics and exercises useful. Found training to be very useful."

"Being with others with similar situations and facing mentoring enthusiastically is good. Emphasising the need to be patient and understanding towards the mentee is good."

"All interesting. Thinking of goals helped think of things we wanted to do moving on. Sharing experiences showed how much we had in common despite

"Training could be a little longer, i.e. (3/4 days). So could do more (pairing up for practical topics)."

"It covers all aspects I can think of. It's done very well."

5.4 Mentoring Partnerships

Table 5.5 shows the number of meetings each pair had, the type of venues where they met, and a summary of their main activities. The number of meetings includes the introductory meeting at which I was present. The subsequent meetings were one-to-one between mentor and mentee.

Table 5.5. Mentoring partnerships.

Mentee	**Mentor**	**No. of meetings**	**Venues**	**Activities**
Mentee Two	Mentor Two	Seven	Marina café	Talking over coffee.
Mentee Three	Mentor Four	Seven	Garden centre café	Talking over coffee. Short

				walks around the garden centre.
Mentee Five	Mentor Three	Three	City centre cafes	Talking over coffee.
Mentee Six	Mentor One	Two	Town centre cafes	Talking over coffee. Short walks in town.

As the results show, only two of the pairs had the full quota of seven meetings. The Mentee Five–Mentor Three partnership had difficulties finding mutually suitable times to meet, before Mentee Five eventually returned to work and decided he did not have the time available to continue with mentoring. Mentee Six had to go back into hospital for a brief time and never resumed mentoring, despite efforts from her mentor and myself to rekindle her interest. The pairs tended to keep to the same venues, which helped with organisation, while the main activity was talking, with some pairs also having some short walks nearby.

5.5 Feasibility Results

This section reports the feasibility results according to the distinctive features of a feasibility study outlined by Orsmond and Cohn (Orsmond and Cohn, 2015) and mapped to the PAIRS study's aims and objectives presented in Section 4.2. My conclusions regarding the feasibility are presented at the end of each section and these will be discussed in detail and elaborated on in the discussion section at the end of the chapter and in Chapter Six.

5.5.1 Recruitment Capability

Objectives:

The target was to recruit fifteen mentees, fifteen mentors, fifteen carers, and fifteen healthcare professionals, with expected attrition accounted for to leave a planned total of ten mentees, ten mentors, five carers and five healthcare professionals (a total of 30 participants with full final datasets). There was no specific time target for recruitment, but the total time from beginning recruitment to conducting final data collection after completion of the intervention was intended to be twelve months. In order to recruit mentors, they first needed to attend and complete training. There were no specific aims for the demographic characteristics of participants, but it was intended that there would be representation of a range of ABI types, age groups, genders, and ethnic groups.

Results:

In order to recruit participants, there were several requirements which had to be met to gain sponsor approval from the University and ethical approval from the Ethics Committee. Firstly, the Sponsor required all mentees to be current patients under NHS rehabilitation services. Then, in December 2017 the University Sponsor stated that mentors would need to be employees of the University so that the University would be legally insured if there were any adverse events. This was considered to be necessary because the intervention required the participants to meet independently and be unsupervised. The issue was addressed by registering the mentors as volunteers with the University, including the requirement for them to have Disclosure and Barring Service (DBS) checks.

The first application to an Ethics Committee in March 2018 was then rejected because, to protect the mentors, the Committee requested that mentees should also have DBS checks. After consultation, my supervisory team appealed this decision on the grounds that it is not permissible to ask research participants to undergo DBS checks, and I submitted a second ethics application to a different committee. The application was approved in June 2018, on the condition that management permission was granted by the host Research and Development department at each mentee recruitment trust. There were then no referrals of eligible mentees in the first few months of recruitment, so I submitted a substantial amendment to change one of the eligibility criteria from <six months post-discharge from hospital after injury, to <twelve months.

When the ethical requirements for eligibility had been finalised, twenty-one potential mentees were identified by the recruitment sites and expressed initial interest. Four were ineligible and eleven withdrew interest. Six provided their consent and completed baseline assessments, of whom two withdrew before the intervention. Recruitment took ten months, ending in March 2018.

Twenty potential mentors applied to take part in the project. Of these, four were ineligible due to living outside the catchment area, three withdrew interest, one was unable to participate in training, and twelve participated in some or all of the training. Nine people completed the training and provided consent to participate as mentors, of whom five were female, four were male, and all were white British.

All four mentors who were matched to participants lived in the surrounding suburbs of Nottingham. Two mentees lived in Nottingham suburbs and two

lived in rural areas of Derbyshire. Of the two mentees who consented but subsequently withdrew, one lived in a Derbyshire town 45 minutes' drive from Nottingham, and one lived in a rural area outside Nottingham. Of the five people who consented to be mentors but were not matched to mentees, four lived in the surrounding suburbs of Nottingham and one lived in rural Derbyshire.

Of the four mentees who participated, three nominated carers who participated in the assessments, and none nominated healthcare providers. Five healthcare providers from the recruitment sites were approached after the intervention, all of whom agreed to participate in post-intervention interviews.

All four mentors who were matched to mentees were female and white British. Three had TBI and one had anoxic brain injury. They were aged 30–49 years. Three mentees were female and one male. Two had strokes, one TBI and one encephalitis. They were aged 51–79. All three carers were white British and aged 52–65. Two were male and one was female. All five healthcare providers were white British and were aged 34–55. Four were female and one was male.

Feasibility conclusions:

- It was not feasible to recruit the target number of mentees via the recruitment sites.
- The eligibility criteria for mentees were not appropriate.
- It was not feasible to recruit the target number of mentors. However, it is potentially feasible to do so via the methods used.
- It is not feasible to recruit carers and healthcare providers via the planned methods.

- It is feasible to recruit healthcare providers from recruitment sites to provide feedback on the recruitment methods.

5.5.2 Data Collection Procedures and Outcome Measures

Objectives:

All mentors and mentees were required to complete a baseline assessment consisting of a demographics section, including information regarding their injury history, and five questionnaires. These were compiled into one booklet and presented face-to-face at participants' homes. They were also asked to state 2–3 goals they would like to achieve from their involvement in the project. There were no postal assessments. I asked the participants the questions and filled in the answers. Carers were asked to complete demographic questions and the Caregiver Burden Scale, which were also presented by me, face-to-face in their homes and completed by me. The participants were all given the same measures (not demographics) after the intervention, which on this occasion were delivered by telephone. I asked the questions and completed the measures. They were also asked to take part in a qualitative interview by telephone, which was conducted by my university colleague BP. The healthcare providers were asked to take part in a qualitative interview by telephone or video call, which I conducted.

Results:

All mentors, mentees, and carers completed the baseline and post-intervention quantitative assessments. All the items on all the questionnaires were completed, so there were no missing data. Each questionnaire was completed in a few minutes and no participants required a break or reported any

difficulties. All the participants completed all the sections of the qualitative interview topic guides, with no breaks required and no questions that anybody could not answer, or did not want to answer. This included the participant with severe aphasia, who completed the questionnaires quickly and with no problems. One mentor was unable to take part in the post-intervention qualitative interview, while one carer declined to participate in the interview. All the healthcare professionals took part in the qualitative interview.

Feasibility conclusions:

- The procedures for data collection were appropriate and feasible.
- The participants were able to complete all the measures.
- The data were complete and useable.

5.5.3 Acceptability and Suitability of Intervention Procedures

Objectives:

Potential mentors were required to attend two training days and complete DBS forms. There were no assessments or specific criteria to pass the training. However, they were assessed for suitability according to the eligibility criteria for mentors by me and a colleague, an occupational therapist who helped me conduct the training.

Mentors and mentees were matched and had introductory meetings with me in attendance. If both parties wished to proceed with the partnership, they were required to meet independently, in the community, a further six times. They were encouraged to engage in enjoyable activities and talk.

Results:

In total, twelve potential mentors attended the training. Eight attended all of both days, two attended only the second day, one attended only the first day, and one had to leave on the second afternoon. In personal communication with me, all attendees expressed their enjoyment of the training and said that it was useful to prepare them to be mentors, while training evaluation forms said that the training was satisfactory and agreeable.

Including the introduction, two pairs (50%) met for the full seven times, one pair met three times, and the other twice. Two mentees withdrew before completing their quota of meetings. Pairs tended to meet in coffee shops to talk. There were no other activities other than brief walks around shopping areas near the coffee shop locations. There were no adverse events. However, there were several difficulties with the organisation of meetings.

Feasibility conclusions:

- The mentor training was suitable and acceptable for participants.
- The training was feasible to deliver in the planned form. However, the fact that not all participants could attend all of both days meant presenting information by telephone, which was an inadequate recreation of the sessions they missed.
- It is feasible for pairs to arrange and attend mentoring meetings.
- The number of meetings required of participants was not feasible for enough pairings.
- The planned social and leisure activities were not feasible.

5.5.4 Resources, Management, and Implementation

Objectives:

The objective was to deliver and manage the study as a lone researcher with limited time and resource availability.

Results:

The multiple delays, amends and re-applications for sponsor and ethics approvals were time consuming and cut into the time available for recruitment and to deliver the intervention. The mentor training required substantial time, resources, and expense to create the content, prepare, organise, and deliver. This included support from an additional staff member to deliver the training, from an administrator to book venues and catering, and from colleagues to attend practice sessions.

Recruitment required researching all possible recruitment sources, making telephone calls and emails to establish contacts, travelling to rehabilitation services across a wide region, preparing and delivering presentations, and maintaining regular contact with the recruitment sites throughout the recruitment period.

It was necessary to travel to the participants' homes to conduct all the baseline assessments and to travel to community venues for introductory meetings. The wide geographical spread of participants often meant travelling substantial distances. Financial resources were required to reimburse participants for all travel and expenses involved with attending training days and mentoring meetings. During the intervention, the participants required frequent contact by telephone before and after meetings to discuss the project and resolve issues. It was necessary to help people to make arrangements and to keep fully up to date

with all plans for times, venues, and activities for all meetings in order to ensure that the wellbeing of all the participants had been accounted for before and after meetings.

Feasibility conclusions:

- The resource requirements were feasible but challenging for a lone researcher.
- The management requirements were feasible but challenging for a lone researcher.
- A larger study of the same type would not be feasible for a lone researcher.
- A larger study would involve a significant increase in the management and resource requirements.
- Peer mentoring is a management- and resource-intensive field of research.

5.6 Quantitative Results

This section provides the results of the fifth feasibility outcome, in addition to those discussed above; the preliminary evaluation of participant responses to the intervention (effectiveness). There follows the baseline and post-intervention quantitative data for participant groups (mentors, mentees, and carers) and combined totals (mentors and mentees). The results for each individual participant are presented after the combined results for each outcome measure, which, because of the small sample size, provide a clearer picture of changes.

The paired samples t-tests are not reported because the small sample size means that it is not meaningful to calculate the significance of the changes. Instead, the direction and size of the changes are reported along with the ranges, standard deviations, and 95% confidence intervals. As a preliminary measure, I conducted tests of normality, for which the histograms showed visually that all data were normally distributed.

Note: Higher scores for the CIQ, HHI, and EQ-5D-5L Visual Analogue Scale indicate better outcomes. Higher scores on the DASS-21, EQ-5D-5L Index, and CBS indicate poorer outcomes.

5.6.1 Community Integration Questionnaire (CIQ)

Tables 5.6 and 5.7 present the results of the CIQ, which was used as a measure of the participation levels of mentees and mentors. Table 5.6 compares the baseline and post-intervention mean scores of the groups of mentees and mentors, while Table 5.7 compares the results at the two timepoints for each individual mentee and mentor.

Table 5.6. Pre- and post-intervention CIQ mean scores.

Scale **(Min–max)**	**Group**	**Baseline:** **Mean (SD); range**	**Post:** **Mean (SD); range**	**Change: Mean (SD)** **95% CI**
CIQ: Home Integration **(0–10)**	Mentees (*n* = 4)	6.88 (2.17); 5.00–10.00	4.38 (2.60); 1.25–7.50	-2.50↓ (1.02) -4.12–0.88
	Mentors (*n* = 4)	6.00 (1.41); 5.00–8.00	6.25 (1.26); 5.00–8.00	0.25↑ (0.50) -0.55–1.05
CIQ: Social Integration **(0–12)**	Mentees (*n* = 4)	9.00 (0.82); 8.00–10.00	10.00 (1.16); 9.00–11.00	1.00↑ (1.41) -1.25–3.25

Scale **(Min–max)**	**Group**	**Baseline:** **Mean (SD); range**	**Post:** **Mean (SD); range**	**Change: Mean (SD)** **95% CI**
	Mentors (*n* = 4)	9.50 (2.65); 6.00–12.00	9.50 (2.65); 6.00–12.00	0.00 =
CIQ: Productivity **(0–7)**	Mentees (*n* = 4)	1.75 (1.26); 0.00–3.00	2.50 (2.38); 1.00–6.00	0.75↑ (1.71) -1.97–3.47
	Mentors (*n* = 4)	5.00 (0.82); 4.00–6.00	5.00 (0.82); 4.00–6.00	0.00 =
CIQ: Total **(0–29)**	Mentees (*n* = 4)	17.63 (2.77); 14.25–21.00	16.88 (2.47); 13.75–19.50	-0.75↓ (0.14) -2.56–1.06
	Mentors (*n* = 4)	20.50 (1.29); 19.00–22.00	20.75 (0.96); 20.00–22.00	0.25↑ (0.50) -0.55–1.05

Key: ↓ Reduced; ↑ Increased; = No change; Higher scores indicate better outcomes.

SD: Standard deviation. CI: confidence interval.

The changes were either small or zero, bi-directional, and without discernible patterns, while the confidence intervals include zero in all cases. There are no clear indications that the intervention improved participation, or more importantly, not as it is measured by the CIQ. However, the most striking change was the reduction of 2.5 in the mean score for mentees on the Home Integration Scale. The confidence interval for this difference (-4.12–0.88) indicates that there would be a probability of replicating the negative result if repeating the intervention, so further investigation of a reason for this would be informative.

Table 5.7. CIQ individual participant results.

ID	Home (0–10)		Social (0–12)		Productivity (0–7)		Total (0–29)	
	Base	Post	Base	Post	Base	Post	Base	Post
Mentee Two	6.25	5.00↓	9	11↑	2	2=	17.25	18.00↑
Mentee Three	6.25	3.75↓	8	9↑	0	1↑	14.25	13.75↓
Mentee Five	5	1.25↓	10	9↓	3	6↑	18	16.25↓
Mentee Six	10	7.5↓	9	11↑	2	1↓	21	19.5↓
Mentor One	8	8=	6	6=	6	6=	20	20=
Mentor Two	6	6=	12	12=	4	4=	22	22=
Mentor Three	5	6↑	9	9=	5	5=	19	20↑
Mentor Four	5	5=	11	11=	5	5=	21	21=

Key: ↓ Reduced. ↑ Increased. = No change. Higher scores indicate better outcomes.

The individual results further illuminate the areas of interest from the presentation of the group means. We again see differences which are small, bi-directional, or zero, within and between participants, indicating that the intervention had no effect. However, the mentees' results on the Home Integration Scale are an exception to this, with all four mentees decreasing post-intervention compared to the baseline. This provides preliminary evidence that, for some reason, the intervention may have had a negative impact on the areas of Home Integration assessed by the scale. For the reader's information and to aid further discussion of this finding at the end of the chapter and in Chapter Five, the items on the Home Integration Scale involve who in the respondent's household shops for groceries, prepares meals, does housework, cares for children, and plans social arrangements.

5.6.2 Depression, Anxiety and Stress Scale (DASS-21)

Tables 5.8 and 5.9 present the results of the DASS-21 sub-scales of depression, anxiety, and stress, which were used to measure the psychological health of mentees and mentors. Table 5.8 compares the baseline and post-intervention mean scores of the groups of mentees and mentors, while Table 5.9 compares the results at the two timepoints for each individual mentee and mentor.

Table 5.8. Pre- and post-intervention DASS-21 mean scores.

Scale (Min–max)	**Group**	**Base: Mean (SD); range**	**Post: Mean (SD); range**	**Change: Mean (SD) 95% CI**
Depression (0–42)	Mentees (*n* = 4)	4.50 (4.12); 0–8	5.50 (7.19); 0–16	1.00↑ (5.77) -8.19–10.19
	Mentors (*n* = 4)	3.50 (4.44); 0–10	4.50 (4.12); 0–8	1.00↑ (3.46) -4.51–6.51
Anxiety (0–42)	Mentees (*n* = 4)	3.00 (4.76); 0–10	8.50 (9.85); 0–18	5.50↑ (7.55) -6.51–17.51
	Mentors (*n* = 4)	1.00 (1.16); 0–2	1.50 (1.92); 0–4	0.50↑ (1.92) -2.55–3.55
Stress (0–42)	Mentees (*n* = 4)	11.00 (10.39); 0–24	14.00 (15.06); 0–28	3.00↑ (6.83) -7.87–13.87
	Mentors (*n* = 4)	12.00 (7.12); 4–18	13.50 (1.92); 12–16	1.50↑ (5.51) -7.26–10.26

Key: ↓ Reduced. ↑ Increased. = No change. Higher scores indicate poorer outcomes.

SD: Standard deviation. CI: confidence interval.

The means increased for mentees and mentors on all three scales, indicating poorer outcomes. However, the changes were all mostly small and from a low baseline level which indicated no clinical levels of depression, anxiety, or stress. There were also wide confidence intervals, all including zero, which showed that the true change could have been either positive or negative. No conclusions can be derived as to the impact of the intervention on these measures. The most striking change, and one which warrants further examination within the individual results, was an increase of 5.5 in anxiety for the mentees.

Table 5.9. DASS-21 individual participant results.

ID	Depression (0–42)		Anxiety (0–42)		Stress (0–42)	
	Base	Post	Base	Post	Base	Post
Mentee Two	8 (Normal)	16↑ (Moderate)↑	10 (Moderate)	16↑ (Severe)↑	24 (Moderate)	28↑ (Severe)↑
Mentee Three	8 (Normal)	2↓ (Normal)=	0 (Normal)	0= (Normal)=	0 (Normal)	0= (Normal)=
Mentee Five	2 (Normal)	4↑ (Normal)=	2 (Normal)	18↑ (Severe)↑	14 (Normal)	26↑ (Severe)↑
Mentee Six	0 (Normal)	0= (Normal)=	0 (Normal)	0= (Normal)=	6 (Normal)	2↓ (Normal)=
Mentor One	10 (Mild)	8↓ (Normal↓)	0 (Normal)	2↑ (Normal=)	18 (Mild)	14↓ (Normal↓)
Mentor Two	2 (Normal)	8↑ (Normal=)	2 (Normal)	0↓ (Normal=)	4 (Normal)	12↑ (Normal=)
Mentor Three	2 (Normal)	2= (Normal=)	2 (Normal)	4↑ (Normal=)	18 (Mild)	16↓ (Mild=)
Mentor Four	0 (Normal)	0= (Normal=)	0 (Normal)	0= (Normal=)	8 (Normal)	12↑ (Normal=)

Key: ↓ Reduced. ↑ Increased. = No change. Higher scores indicate poorer outcomes.

Examination of the individual scores is revealing and illuminates the group analysis. We can see that there were striking changes for Mentees Two and

Five, many of which crossed thresholds indicating possible clinical levels post-intervention. Mentee Two increased from Normal to Moderate for depression and Moderate to Severe for both anxiety and stress. Mentee Five, while having only a slight change for depression, increased from Normal to Severe levels for both anxiety and stress. The lack of any other notable changes for any other participants on any scales suggests that there were specific issues affecting these two participants.

5.6.3 EuroQol EQ-5D-5L

Tables 5.10 and 5.11 present the results of the EQ-5D-5L Index and the Visual Analogue Scale, which were used to measure the quality of life of the mentees and mentors. Table 5.10 compares the baseline and post-intervention mean scores of the groups of mentees and mentors, while Table 5.11 compares the results at the two timepoints for each individual mentee and mentor.

Table 5.10. Pre- and post-intervention EQ-5D-5L scores.

Scale **(Min–max)**	**Group**	**Base:** **Mean (SD); range**	**Post:** **Mean (SD); range**	**Change: Mean (SD)** **95% CI**
EQ-5D-5L: Index **(0.20–1.00)**	Mentees (*n* = 4)	0.44 (0.22); 0.20–0.68	0.39 (0.18); 0.20–0.56	-0.05↓ (0.05) -0.13–0.03
	Mentors (*n* = 4)	0.33 (0.12); 0.20–0.48	0.37 (0.12); 0.20–0.48	0.04↑ (0.05) -0.03–0.11
EQ-5D-5L: Visual Analogue Scale (VAS) **(0–100)**	Mentees (*n* = 4)	76.88 (17.25); 62.5–100.0	72.50 (21.02); 50.0–100.0	-4.38↓ (7.74) -16.69–7.94
	Mentors (*n* = 4)	77.75 (14.08); 65.0–94.0	75.75 (13.38); 60.0–90.0	-2.00↓ (8.25) -15.12–11.12

Key: ↓ Reduced. ↑ Increased. = No change. Higher scores on the EQ-5D-5L Index indicate poorer outcomes. Higher scores on the Visual Analogue Scale indicate better outcomes. SD—Standard deviation; CI—Confidence interval; VAS—Visual Analogue Scale.

The results show very small changes and relatively small confidence intervals encompassing zero. These results suggest the participants were stable in these areas and that the intervention had a negligible impact. The scores suggested that, overall, the groups had some physical impairments but a good overall physical quality of life.

Table 5.11. EQ-5D-5L individual participant results.

ID	Mobility (1–5)		Self-care (1–5)		Usual activities (1–5)		Pain and discomfort (1–5)		Anxiety (1–5)		Health Index (0.20–1.00)		Visual Analogue Scale (VAS) (0–100)	
	B	P	B	P	B	P	B	P	B	P	B	P	B	P
Mentee Two	3	3=	3	3=	3	3=	2	1↓	3	3=	0.56	0.52↓	65	50↓
Mentee Three	2	2=	1	2↑	3	1↓	1	1=	1	1=	0.32	0.28↓	80	75↓
Mentee Five	4	4=	3	2↓	3	3=	4	4=	3	1↓	0.68	0.56↓	62.5	65↑
Mentee Six	1	1=	1	1=	1	1=	1	1=	1	1=	0.20	0.20=	100	100=
Mentor One	1	2↑	1	1=	1	2↑	2	2=	2	2=	0.28	0.36↑	67	60↓
Mentor Two	4	4=	1	2↑	1	2↑	2	2=	1	1=	0.36	0.44↑	94	83↓
Mentor Three	3	3=	1	1=	3	3=	3	3=	2	2=	0.48	0.48=	65	70↑
Mentor Four	1	1=	1	1=	1	1=	1	1=	1	1=	0.20	0.20=	85	90↑

Key:↓ Reduced. ↑ Increased. = No change. Higher scores on the EQ-5D-5L Scale indicate poorer outcomes. Higher scores on the Visual Analogue Scale indicate better outcomes.

Most of the changes in Index scores among mentees were improvements. These included improvements for Mentees Two and Five, who both

deteriorated markedly on the DASS-21. Mentee Five even showed an improvement for anxiety on the EQ-5D-5L, despite changing from Normal at baseline to Severe post-intervention for anxiety on the DASS-21. Surprisingly, the changes for mentors were slight deteriorations, specifically for Mentor One in Mobility and Usual Activities, and Mentor Two for Self-care and Usual Activities.

5.6.4 Herth Hope Index (HHI)

Tables 5.12 and 5.13 present the results for the Herth Hope Index, which was used to measure the concept of hope for the future among mentees and mentors. Table 5.12 compares the baseline and post-intervention mean scores of the groups of mentees and mentors, while Table 5.13 compares the results at the two timepoints for each individual mentee and mentor.

Table 5.12. Pre- and post-intervention Herth Hope Index scores.

Scale **(Min–max)**	**Group**	**Base:** **Mean (SD); range**	**Post:** **Mean (SD); range**	**Change: Mean (SD)** **95% CI**
Herth Hope Index **(12–48)**	Mentees (*n* = 4)	42.00 (5.48); 37–47	42.00 (5.48); 34–46	0.00= (3.56) -5.66–5.66
	Mentors (*n* = 4)	40.00 (4.08); 34–43	41.25 (4.92); 34–45	1.25↑ (1.89) -1.76–4.26

Key: ↓ Reduced. ↑ Increased. = No change. Higher scores indicate better outcomes. SD—Standard deviation; CI—confidence interval.

There were no notable changes. The improvement of 1.25 for mentors had a small standard deviation and confidence interval, spanning zero, indicating a robust stability in the results at the two timepoints. It is reasonable to suppose that the mentor group would exhibit only minor changes in this measure if the

assessments were repeated. While the mean score for the mentees remained exactly the same, the confidence interval of -5.66–5.66 suggests that there was some variability between the participants which might indicate outliers. This warrants further investigation in the individual results.

Table 5.13. Herth Hope Index individual participant results.

ID	Baseline	Post
Mentee Two	37	34 ↓
Mentee Three	38	43 ↑
Mentee Five	47	45 ↓
Mentee Six	46	46 =
Mentor One	34	34 =
Mentor Two	42	43 ↑
Mentor Three	41	45 ↑
Mentor Four	43	43 =

Key: ↓ Reduced ↑ Increased = No change Higher scores indicate better outcomes

The mentor's scores were largely stable, although there was a marked improvement for Mentor Three. As suggested by the group means, there was comparatively wide variation in changeability among the mentees, with two deteriorations and one improvement, all by two–five points.

5.6.5 Caregiver Burden Scale (CBS)

Tables 5.14 and 5.15 present the results of the Caregiver Burden Scale, which was used to measure the concept of carer burden amongst carers of the mentees in the study. Table 5.14 compares the baseline and post-intervention mean scores of the group of three carers, while Table 5.15 compares the results at the two timepoints for each individual carer.

Table 5.14. Pre- and post-intervention CBS scores (n = 3).

Scale (Min–max)	Base: Mean (SD); range	Post: Mean (SD); range	Change: Mean (SD) 95% CI
CBS (0–88)	20.00 (13.12); 6–32	16.67 (14.30); 2–29	-3.33↓ (1.53) -7.13–0.46

Key: ↓ Reduced. ↑ Increased. = No change. Higher scores indicate poorer outcomes. SD—Standard deviation; CI—confidence interval.

Although the sample size was very small, the confidence interval, which includes zero but is mainly negative, suggests a high probability that the true change was, indeed, a reduction in burden. The mean baseline score was low (20, with a range of 6–32, from a maximum of 88), suggesting the carers did not feel high levels of burden.

Table 5.15. CBS individual participant results.

ID	Baseline	Post
Carer 1	32 (Mild to moderate)	29↓ (Mild to moderate) =
Carer 3	22 (Mild to moderate)	20↓ (No or minimal)↓
Carer 4	6 (No or minimal)	1↓ (No or minimal) =

Key: ↓ Reduced. ↑ Increased. = No change.

All three carers showed an improvement, with one crossing a threshold from ‘Mild to moderate’ burden to ‘No or minimal’ burden. Although the changes were small and the perceived burden was low, the results suggest that there was a real reduction over the course of the intervention.

5.6.6 Individual Goals

Table 5.16 shows the goals set by participants for what they would like to achieve from their involvement in the project. These are categorised into those that the participants stated they had achieved and those they had not.

Table 5.16. Intervention goals.

ID	Goal	Achieved	Not achieved
Mentee Two	Talk to somebody who understands what you have been through and what it is like now	X	
	Have a reason to get out more	X	
Mentee Three	Meet people	X	
	Go for walks	X	
	Go shopping		X
Mentee Five	Gain knowledge of the condition	X	
	Gain self-acceptance	X	
	Increase social activities		X
Mentee Six	Understand more about the problems caused by brain injury		X
	Become more able to help other people		X
	Increase social activities		X
Mentor One	Meet new people	X	
	Pass on the benefit of experience	X	
Mentor Two	Be there for someone else who is still working out how to live with the injury	X	
	Do something useful	X	
	Help someone else meet their goals	X	
Mentor Three	Support someone else with an injury	X	
	Remind yourself how much progress you have made	X	
	Do something for someone else you would have wanted when you first got injured	X	

ID	Goal	Achieved	Not achieved
	Get out and do something different	X	
Mentor Four	Use the brain injury for something positive	X	
	Do something good for someone else	X	
	Meet other people with brain injuries	X	

All the mentors achieved all their goals from their involvement. One mentee failed to achieve any of their three goals, one achieved two/two, and two achieved two/three. Two failed to achieve the goal of increasing social activities, which suggests that they did not consider meeting the mentor to be a social activity but wanted the mentoring to help them find other social activities.

5.6.7 Peer Mentoring Questionnaire (PMQ)

The following sections present the results of the PMQ assessing the intervention's perceived impact on mentees (mentors and carers answered according to their view of the effect on the mentee). The numbers in the columns represent the number of responses to each option for the item to which they refer.

PMQ–Empowerment and Quality of Life

Table 5.17 presents the results of the Peer Mentoring Questionnaire (PMQ) section regarding empowerment and quality of life. The items relate to

perceived control and agency when coping with everyday life, and overall quality of life.

Table 5.17. PMQ–Empowerment and Quality of Life.

Item	Participant group	No help	Some help	Great deal of help	Don't know	Total
Ability to Deal with Life	Mentees	1	1	1	1	4
	Mentors	1	2	0	1	4
	Carers	1	1	1	0	3
	Total	3	4	2	2	11
Control over Life	Mentees	2	2	0	0	4
	Mentors	2	1	0	1	4
	Carers	2	0	0	1	3
	Total	6	3	0	2	11
Overall Quality of Life	Mentees	2	2	0	0	4
	Mentors	0	2	1	1	4
	Carers	2	0	1	0	3
	Total	4	4	2	1	11

Key: Numbers refer to the number of participants who selected the answer in the column.

Respondents: Mentors = 4; Mentees = 4; Carers = 3

As with all the other sections of the PMQ, there was a 100% response rate for all the items. Mentoring was considered to be more helpful for mentees' ability to deal with life than for their control over life. Therefore, coping appears to be an important outcome rather than agency/control. Half of the mentees said that mentoring helped them in each of the three areas and over half of all respondents said that mentoring improved the mentee's overall quality of life. While there was a spread of responses across all options, this section of the PMQs indicates some effectiveness for the mentees in the project.

PMQ–Mood

These items relate to mentoring's perceived impact on the mentee's happiness, depression, anger, and anxiety. Table 5.18 presents the response rates for each item.

Table 5.18. PMQ–Mood.

Item	Participant group	No help	Some help	Great deal of help	Don't know	Total
Amount of Happiness	Mentees	1	2	1	0	4
	Mentors	1	3	0	0	4
	Carers	2	1	0	0	3
	Total	4	6	1	0	11
Amount of Sadness/Depression	Mentees	2	1	1	0	4
	Mentors	0	4	0	0	4
	Carers	2	1	0	0	3
	Total	4	6	1	0	11
Amount of Anger	Mentees	4	0	0	0	4
	Mentors	1	1	0	2	4
	Carers	3	0	0	0	3
	Total	8	1	0	2	11
Amount of Anxiety	Mentees	2	2	0	0	4
	Mentors	0	3	1	0	4
	Carers	2	1	0	0	3
	Total	4	6	1	0	11

Key: Numbers refer to the number of participants who selected the answer in the column.

Respondents: Mentors = 4; Mentees = 4; Carers = 3

The majority of participants thought that mentoring helped with anxiety, depression, and happiness. Only one said that the intervention had any impact on their amount of anger. All the mentors said that mentoring helped with their mentee's anxiety and sadness/depression. These results suggest that improving happiness and relieving anxiety and depression are effective outcomes of mentoring.

PMQ–Skills and Knowledge

The items in this section of the PMQs, presented in Table 5.19, relate to knowledge and understanding of the injury, the impact on health, helpful resources and services, and communication with healthcare professionals.

Table 5.19. PMQ–Skills and Knowledge.

PMQ	Participant group	No help	Some help	Great deal of help	Don't know	Total
Communication with Healthcare Professionals	Mentees	3	1	0	0	4
	Mentors	3	1	0	0	4
	Carers	2	1	0	0	3
	Total	8	3	0	0	11
Knowledge about Brain Injury	Mentees	3	1	0	0	4
	Mentors	0	2	2	0	4
	Carers	2	0	0	1	3
	Total	5	3	2	1	11
Knowledge about Community Resources	Mentees	4	0	0	0	4
	Mentors	2	2	0	0	4
	Carers	2	0	0	1	3
	Total	8	2	0	1	11
	Mentees	1	2	1	0	4

PMQ	Participant group	No help	Some help	Great deal of help	Don't know	Total
Understanding of Health Issues	Mentors	2	1	1	0	4
	Carers	2	1	0	0	3
	Total	5	4	2	0	11
Knowledge of Services	Mentees	4	0	0	0	4
	Mentors	2	2	0	0	4
	Carers	2	0	0	1	3
	Total	8	2	0	1	11

Key: Numbers refer to the number of participants who selected the answer in the column.

Respondents: Mentors = 4; Mentees = 4; Carers = 3

The majority of participants said that mentoring was no help with improving communication with healthcare professionals, knowledge of community resources, or knowledge of services. These results suggest that the intervention did not have the desired effect of conveying information about resources and services. There was a discrepancy between groups regarding the perceived impact of mentoring on knowledge about brain injury, with all mentors stating that mentoring was helpful but only one mentee or carer agreeing. Responses from mentees suggested that they gained most in understanding of health issues, with three out of four saying the intervention was helpful.

PMQ–Social Support

These items relate to the help mentoring provided to mentees for accessing support from sources other than their mentor, such as family, friends, the community, and support groups. Mentors could help with this by providing information about useful organisations, talking about difficulties with family

members and friends, or accompanying mentees to support groups. Table 5.20 presents the results of the Social Support section.

Table 5.20. PMQ–Social Support.

PMQ	Participant group	No help	Some help	Great deal of help	Don't know	Total
Support from Family	Mentees	3	0	1	0	4
	Mentors	3	1	0	0	4
	Carers	3	0	0	0	3
	Total	9	1	1	0	11
Support from Friends	Mentees	2	1	1	0	4
	Mentors	3	0	0	1	4
	Carers	3	0	0	0	3
	Total	8	1	1	1	11
Support from the Community	Mentees	4	0	0	0	4
	Mentors	3	1	0	0	4
	Carers	3	0	0	0	3
	Total	10	1	0	0	11
Learning More about Friends and Social Issues	Mentees	4	0	0	0	4
	Mentors	4	0	0	0	4
	Carers	2	1	0	0	3
	Total	10	1	0	0	11
Getting a New Support Group	Mentees	4	0	0	0	4
	Mentors	4	0	0	0	4
	Carers	2	1	0	0	3
	Total	10	1	0	0	11

Key: Numbers refer to the number of participants who selected the answer in the column.

Respondents: Mentors = 4; Mentees = 4; Carers = 3

The results indicate that most participants did not find mentoring helpful in these areas. Indeed, no mentees found the intervention helpful in any area except support from family. However, it is interesting to note that one mentee found mentoring a great deal of help in that area.

PMQ–Practical Issues

This section related to the impact of mentoring on a variety of pragmatic and administrative issues. The purpose was to identify whether mentors were able to pass on information relevant to these everyday concerns, which are essential but often difficult skills. Table 5.21 presents the participants' responses.

Table 5.21. PMQ–Practical Issues.

PMQ	Participant group	No help	Some help	Great deal of help	Don't know	Total
Financial Concerns	Mentees	4	0	0	0	4
	Mentors	4	0	0	0	4
	Carers	3	0	0	0	3
	Total	11	0	0	0	11
Dealing with Family Issues	Mentees	4	0	0	0	4
	Mentors	3	1	0	0	4
	Carers	3	0	0	0	3
	Total	10	1	0	0	11
Housing	Mentees	4	0	0	0	4
	Mentors	4	0	0	0	4
	Carers	3	0	0	0	3
	Total	11	0	0	0	11
Work	Mentees	4	0	0	0	4
	Mentors	4	0	0	0	4

PMQ	Participant group	No help	Some help	Great deal of help	Don't know	Total
	Carers	3	0	0	0	3
	Total	11	0	0	0	11

Key: Numbers refer to the number of participants who selected the answer in the column.

Respondents: Mentors = 4; Mentees = 4; Carers = 3

The results of this section very clearly show that mentoring was not considered to be helpful in these areas. The only exception was one mentor, who thought that there was some benefit for dealing with family issues, but mentees stated 'No help' on all items.

PMQ–Emotional Adjustment

This section asked questions pertaining to the mentees' emotional and psychological adjustment to the difficult or traumatic aspects of life and their ability to cope with them. The results are presented in Table 5.22.

Table 5.22. PMQ–Emotional Adjustment.

PMQ	Participant group	No help	Some help	Great deal of help	Don't know	Total
Getting Meaning from a Terrible Event	Mentees	3	1	0	0	4
	Mentors	0	2	0	2	4
	Carers	2	0	1	0	3
	Total	5	3	1	2	11
Feeling of Belonging	Mentees	3	1	0	0	4
	Mentors	3	1	0	0	4
	Carers	3	0	0	0	3
	Total	9	2	0	0	11
	Mentees	2	1	1	0	4

PMQ	Participant group	No help	Some help	Great deal of help	Don't know	Total
Decreasing Feelings of Being Alone	Mentors	1	1	2	0	4
	Carers	1	1	1	0	3
	Total	4	3	4	0	11
Learning about Emotional Distress	Mentees	4	0	0	0	4
	Mentors	1	2	0	1	4
	Carers	2	1	0	0	3
	Total	7	3	0	1	11

Key: Numbers refer to the number of participants who selected the answer in the column.

Respondents: Mentors = 4; Mentees = 4; Carers = 3

The majority of participants did not think the intervention was useful at all for improving feelings of belonging or learning about emotional distress. However, at least one mentee said that there was some help with getting meaning from a terrible event, feelings of belonging, and decreasing feelings of being alone. The intervention was perceived as most useful for decreasing feelings of being alone, with four participants saying it was a great deal of help.

PMQ–Satisfaction with the Programme

The final section of the PMQ asked participants to rate their satisfaction with the mentoring intervention. This short section presented questions related to the meetings and partners. The results are presented in Table 5.23.

Table 5.23. PMQ–Satisfaction with the Programme.

PMQ	Participant group	Too short	Too long	Just right	Don't know	Total
	Mentees	0	0	4	0	4
	Mentors	1	0	3	0	4

Length of Mentoring Sessions	Carers	1	0	2	0	3
	Total	2	0	9	0	11
		Not often enough	**Too often**	**Just right**	**Don't know**	**Total**
Number of Meetings	Mentees	1	0	2	1	4
	Mentors	2	0	2	0	4
	Carers	2	0	1	0	3
	Total	5	0	5	1	11
		Not	**Somewhat**	**Very**	**Don't know**	**Total**
How Satisfied with Mentor	Mentees	0	0	3	1	4
	Mentors	NA	NA	NA	NA	NA
	Carers	0	0	2	1	3
	Total	0	0	5	2	7
How Comfortable with Partner	Mentees	0	1	3	0	4
	Mentors	0	0	4	0	4
	Carers	0	1	2	0	3
	Total	0	2	9	0	11

Key: Numbers refer to the number of participants who selected the answer in the column.

Respondents: Mentors = 4; Mentees = 4; Carers = 3. For the items 'How satisfied with mentor' and 'How comfortable with partner' carers were asked to provide their perception of the mentee's view.

The five participants who said that there were not enough meetings were all involved in partnerships that ended early. The people who had the full quota of meetings all stated that the number was just right. Most participants said that the length of sessions was just right, although one mentor said that one hour might be too short. All mentors were very comfortable with their mentee. Only one mentee stated that they did not know how satisfied they were with their mentor, and this may have related to the partnership which ended after one meeting.

5.7 Qualitative Results

5.7.1 Mentor, Mentee, and Carer Interviews

I identified five main themes arising from the interviewees' experiences of the intervention, each divided into related sub-themes:

Theme One: Practical Issues for Meetings and Activities.

Theme Two: Benefits of Peer Mentoring.

Theme Three: Training and Support Needs of Participants.

Theme Four: Suitability and Compatibility.

Theme Five: Peer Mentoring Providers.

Each theme (with the exception of Theme Five) encompasses several recurring sub-themes. Definitions of these sub-themes, their relationship to the ICF and BCW, and example quotes are provided in Appendix 14.

Theme One: Practical Issues for Meetings and Activities

This theme encompassed a variety of practical factors which impacted on the organisation of meetings and participation in activities during meetings. The theme encompasses the following six sub-themes which recurred across the interviews: 1) physical and sensory impairments; 2) making arrangements; 3) motivation; 4) transport; 5) external circumstances and commitments; and 6) number and duration of meetings.

Physical and Sensory Impairments

Physical impairments, such as mobility problems, limited the activity options for some pairs:

"Mum is quite frail and she's not very strong on her feet and I just suggested that they went for a coffee each time rather than doing something that might have tired mum out or something that she wouldn't have been happy doing." Carer One

The physical difficulties prevented some participants from attempting sport and leisure activities:

"One of the problems was that a lot of the suggestions that were made were to go…bowling or pitch and putt, things that are very physical. Physically I couldn't do things. I can't walk, I can't move very well and I've got a bad hand. So, anything we did involved sitting down, non-physical." Mentee Five

Making Arrangements

The pairs were required to make their own arrangements for meetings, so planning, organisation, and communication were important. This could be challenging for those with cognitive problems, communication difficulties, or competing demands on their time. One mentee was unable to communicate with the mentor due to severe aphasia, so her carer (son) liaised with the mentor to plan the meetings at times that suited the mentee's needs:

"She would pick her up at the same time, at the same place and go for a coffee and catch-up and then drop her back afterwards. And we arranged 11 o'clock in the morning each time when mum's best…So I can't think of any way that that arrangement that we had could be improved really." Carer One

If meetings were not organised in advance so efficiently, then problems occurred. This was particularly problematic when combined with other factors, such as other commitments and travel difficulties:

> *"But that's why we didn't meet as often because she couldn't get into the city because of her babysitting issues and I couldn't get into the city because I can't physically go anywhere without assistance. So it became difficult to meet up because of the locality that we both had."* Mentee Five

Lack of effective communication between pairs caused problems with organisation, because sometimes it was difficult for people to contact each other. The mentors each had a pay-as-you-go phone specifically for the project, but they often did not switch them on or keep them charged:

> *"If you wanted to rearrange or cancel like a couple of days beforehand, which has happened one time, of course the phone isn't switched on, so you don't even know."* Mentor Three

Motivation

The participants reported that they were happy to meet for a coffee, without planning any other activities:

> *"We didn't have any plans. We just met up, had a coffee, then went home."* Mentee Five

This suited people, kept things simple and allowed them to concentrate on talking. Therefore, they were not motivated to make more complicated arrangements:

“No, we just went for coffee and went round a garden centre. That’s what she wanted to do and that suited me too.” Mentor Four

Transport

Getting to and from meetings could be challenging for those who were unable to drive and were reliant on public transport:

"[Mentee] can’t walk too far, so it had to be somewhere that was near a bus route…So, yeah, it took a lot of planning...We live in different areas of [town] and neither of us drive, so it was all like public transport and yeah, it was just too much for him to do it." Mentor Three

Having a mentor with a car was beneficial. One mentor was able to pick up her mentee from home and drive to their meeting place, which removed all transport problems for the mentee:

"Obviously from mum’s point of view it was really important that [mentor] could drive, because obviously mum’s not able to." Carer One

External Circumstances and Commitments

Participating in a peer mentoring relationship requires a substantial time commitment, which can be difficult to fit around other priorities. For example, one mentee in the study returned to work during the project and was unable to continue meeting the mentor:

"Because he was working a bit as well and I do a bit of part time work, as well, so it was just trying to fit it all around the commitments…We didn’t manage all the sessions because he went back to work." Mentor Three

Holidays, family commitments, other priorities, and illness also affected the availability of some participants:

> *"She was away. Then I couldn't make it, I was away. We couldn't meet up in another period of time, so then we just gave up."* Mentee Five

Number and Duration of Meetings

Two of the four pairs successfully met the quota of seven meetings, and they considered it to be an appropriate amount:

> *"I think the six to eight sessions is also really good, that's good timing."* Mentor Four

> *"It wasn't too many and it wasn't too few."* Carer One

Those who did not fulfil the quota felt that the two or three meetings they had were not sufficient:

> *"Three times. It wasn't enough."* Mentee Five

One-hour meetings were considered to be perfectly suitable for meeting for coffee and a chat:

> *"The hour-long meetings suited [mentee] perfectly."* Carer One

However, one mentor made the point that the duration of meetings should be flexible according to requirements:

> *"I think that the set time of a meeting for an hour could be more flexible. An hour is very, very quick, so maybe that could depend on activities that people are doing or the needs of the mentee."* Mentor Four

Theme Two: Benefits of Peer Mentoring

The second theme relates to the positive effects mentoring had on mentees and mentors. This encompasses the following five sub-themes: 1) impartiality; 2) shared experience; 3) impact on mentors; 4) individualised support; and 5) social contact.

Impartiality

It was considered important to have somebody impartial to speak to. This allows people to be honest about their feelings without worrying about upsetting family members:

> *"Because, you know, if you want to cry and be so angry and upset about it, it's hard to do that sometimes with your family and friends because you don't want to upset them. And, actually, having someone who you don't know, that can be really powerful, I think."* Mentor Three

Similarly, the fact that a mentor is not professionally involved in the mentee's medical care makes it easier to discuss personal issues and negative feelings with them than with a clinician:

> *"I think some of the questions he wouldn't have wanted to ask professionals because it was quite personal to his situation. So, maybe in terms of relationships, the tolerance for his children, grandchildren, noise, and I think not wanting to concern family members or professionals."* Mentor Three

Shared Experience

Both mentees and mentors said that speaking to another brain injury survivor provided understanding and reassurance. One mentee expressed the frustration caused by the lack of understanding shown by many people who do not have a brain injury:

> *"I found it helpful to talk to somebody, obviously, that had experienced similar and was going through similar things. It was nice just to talk to somebody who felt frustrated sometimes with other people who don't understand."* Mentee Two

Impact on Mentors

All three of the mentors interviewed derived a sense of satisfaction from helping someone else. Feeling useful and doing something good for other people made them feel good about themselves:

> *"Just knowing that you're being useful, just knowing that I'm doing something good, that I'm helping someone, that it's making me feel useful. It's not altruistic. I'm not saying that I'm helping someone so it's good that I'm helping someone. It makes me feel good helping someone."* Mentor Four

The mentors felt that they would have appreciated a peer mentor themselves when they were recovering, so it was important to give someone else the opportunity:

> *"It was just a case of I wanted to help out. I didn't have this opportunity when I had my TBI…It makes me feel good that I can give something back."* Mentor One

Mentoring gave a feeling of meaning and purpose to their own injuries and the hardships they had been through:

> *"Feeling that your injury has helped, is at least helping someone else. At least there's a purpose to something bad happening. Feeling that something good has come out of something bad."* Mentor Four

The mentors also enjoyed the social aspect of mentoring. Participating in the project gave them the opportunity to meet new people:

> *"I enjoy actually meeting people because I don't get to meet that many people anyway. So it was good to meet someone different. It was good to meet someone different and to just actually talk about each other's experiences."* Mentor One

Individualised Support

Several participants said that a strength of peer mentoring is that it can be adapted to meet the goals and needs of each individual mentee:

> *"So I would say surely that's got to be an individual…In the end, they've just got to feel happy and better about their situation, whatever they think is important to make better and change, to improve. For people with different brain injuries, that will be very different, won't it?"* Mentor Four

Social Contact

Social isolation is a major problem for many brain injury survivors. Peer mentoring can help to alleviate this by providing an opportunity to meet

someone else and talk. One of the carers in the project was particularly grateful for the companionship the mentor gave his mother:

> *"The most important thing from mum's point of view, or one of the most important things, is it's additional company for her. Because, you know, she's in a flat on her own…it's additional company, isn't it, and that mental stimulation is really important."* Carer One

Theme Three: Training and Support Needs of Participants

This theme drew together the participants' views on the help and support needed to facilitate involvement in the project for mentees and mentors. The following three sub-themes recurred across the interviews: 1) training and information; 2) support from the researcher; and 3) mentor-to-mentor support.

Training and Information

The mentors provided positive feedback on the training workshops they attended. They enjoyed having the opportunity to meet other people with brain injuries and found the training itself beneficial:

> *"I met a lot of people who had similar things, a range of brain injuries and that was really, really useful. And [the] training was really, really useful."* Mentor Four

Some mentors said they would have liked more information on supporting people with diverse types of brain injury:

> *"Maybe if I'd understood a bit more about that [stroke], that might have helped. So, maybe in the training, maybe that could have been talked about a bit more or made clearer."* Mentor Three

Some also said that it would have been useful to have ongoing advice available from specialist experts to deal with issues that arose with their mentee:

> *"I think sometimes when your mentee's raising questions about is this normal? What can I do about this? I've tried this, this doesn't work…then maybe it might be useful to have a brain injury advisor that you could talk to as well."* Mentor Three

And, crucially, mentors must be confident about the protocols and procedures to follow if there are any safeguarding issues:

> *"Safeguarding, if you feel like someone really is hiding something, or is more than depressed, or having, you know, real tricky thoughts, suicidal thoughts, anything like that, what exactly you should do about that."* Mentor Three

Support from the Researcher

All three mentors and one carer said the support received from the researcher provided reassurance and facilitated a positive experience:

> *"[The researcher] was very good, [the researcher] was fantastic about always following up, and listening, and really having a lot of time and I can't praise him enough for that. That was really supportive."* Mentor Three

It was considered important that the researcher maintained regular contact and was readily available if needed, even if there were no specific problems:

> *"[The researcher] was always at the other end of the phone. I could email him. I do feel that if there'd have been a problem or anything, I'd*

have definitely been able to contact him, but I didn't really have to. We spoke at the beginning of the meetings or at the end of the meetings and he was very, very supportive." Mentor Four

Mentor-to-Mentor Support

Mentors expressed a desire for mentor-to-mentor support, such as additional training sessions, debriefing sessions, and an online group:

"It would have been nice to have more contact with some mentors, sort of while it was going on…see how they were getting on with theirs…At the very end, it would be really, really nice to meet up with all the other mentors and debrief." Mentor Four

Theme Four: Suitability and Compatibility

This topic encompasses the following four sub-themes which deal with the suitability, compatibility and matching of partners: 1) type of injury and effects of injury; 2) personality; 3) traits of a good mentor; and 4) timing for mentees.

Type of Injury and Effects of Injury

The mentees were all matched to a mentor with a different type of injury, and three reported that they would have preferred someone with a similar injury and experience of recovery. The mentees said that the difference in experiences caused a lack of mutual understanding:

"She didn't understand my situation and I couldn't fully appreciate and understand hers. I mean, mine was an injury to the brain caused by a stroke which had physical effects. Her injury is more mental. Therefore, we weren't on the same page regarding that." Mentee Five

In contrast to the mentees, mentors all reported that the differences in the nature of injury were not important, despite having initial misgivings. One mentor reported that it was more important to have other things in common:

> *"At the very beginning I was a bit disappointed because I wanted to meet someone that had had something similar happen to them…but as soon as I met [mentee] and I realised that we had a lot in common and it was still going to be useful to me and her, then I sort of forgot about that. So in the end, it didn't matter"* Mentor Four

Personality

The interviewees commonly referred to issues related to personality and to how well they got on with their partner:

> *"We got on. If you don't get on with the person who you're doing it for then…that's a problem, isn't it?"* Mentor One

One carer spoke highly of the rapport and common ground his mother and her mentor had, which was integral to the success of their partnership:

> *"Mum is very sociable so I'm not surprised that her and [mentor] got on so well…I think, you know, they're going to see each other now as friends anyway so the project has introduced two people who are now friends, which is great…And mum speaks very fondly of her and enjoys her company."* Carer One

That partnership developed into a friendship due to the comfortable and relaxed way the pair got on, and the feeling of mutual support it created for the mentor:

"Friends. I'd say we became friends. It was a very relaxed, very comfortable, it was quite supportive. I think we sort of supported each other." Mentor Four

Traits of a Good Mentor

Being a good listener was referred to as an important trait for mentors:

"[Mentor] is a very good listener - she's a very attentive listener as well" Carer One

This was frequently referred to as an active process, involving attentive listening and responding appropriately at the right times. These are all aspects of good communication skills:

"Communication skills. Listening, primarily, but also talking…Basically, to talk about things and to also listen to things and give advice." Mentee Five

One mentor said that it is important to pay attention and remember that peer mentoring is primarily about the needs of the mentee:

"And definitely kind of a good listener, I think, would be one of the main things, as well, because it is more important that the mentee talks, and that you listen, I think, in terms of dynamic." Mentor Three

Listening was particularly important for the mentee with severe aphasia, because allowing her the time to get her point across took patience and skill:

"I was very conscious to make sure that she was able to say the things that she could say and she got the time to put across things that were

important to her. So yes, even though she couldn't talk, it was still very important to listen." Mentor Four

One mentor pointed out the importance of thinking about arrangements from the mentee's point of view:

"And I think to be quite aware because, you know, I could see when he was getting very tired or just thinking about if we'd meet there, he's getting obstacles there, how's he going to walk there?" Mentor Three

Openness and adaptability were seen as important:

"Being able to listen, being supportive, being open, so if she had wanted or needed to do different things, there'd be no problem." Mentor Four

Insight and self-awareness were also cited as key qualities. To help others, a mentor must have insight into their own impairments:

"You have to have knowledge of your own difficulties, because there's no point in having someone who has had it for a long time but doesn't really know how to deal with their own emotional state or understand certain things." Mentor One

It is crucial that mentors are trustworthy and dependable, especially with vulnerable mentees:

"Trustworthy, yes, very much so…I had complete trust in her that she would be able to meet mum, get her into the car, look after her for that hour and bring her back safely." Carer One

One mentor cited the importance of having a balance between positivity and realism:

> *"I think you have to, being realistic, it is absolutely horrible having a brain injury…but, at the same time, you know, not too many negatives. I guess being balanced on the whole, being quite positive about who you are now."* Mentor Three

Timing for Mentees

It was seen as important that mentees receive mentoring at the right time. Participants stated the importance of mentees having good insight and self-awareness, which can take time to develop, so mentoring should not come too soon after the injury:

> *"I think definitely anyone with a brain injury of any sort would definitely benefit from it. But that's only if they want it…If you do it too soon, they're either going to believe that they have nothing wrong with them, like I did (laughs), or they're just not going to know anything."* Mentor One

However, if a person has already achieved their recovery goals, then the opportunity may have been missed:

> *"But it can't be too late because, if it's too late, then it'd be like, well I've done it all now, why are you offering me help?"* Mentor One

This is highlighted by the experience of one mentee, who felt it took too long to match her with a mentor, and by then the ideal time for mentoring had passed:

> *"I think when it started, it took quite a long time to organise. It took over six months before I actually got a mentor and, by then, I'd started to go out a little bit anyway. So it was a bit late, really."* Mentee Two

Theme Five: Peer Mentoring Providers

Participants were asked which service providers would be best able to deliver peer mentoring in the future. Overall, the participants thought that the NHS would be best placed to provide peer mentoring. One mentor said that NHS providers would be able to select the best mentors due to their familiarity with people with the right qualities:

> *"I think it would be better if it was through the NHS, to be honest, because then they would be allocating mentors and they would have knowledge of the mentor prior."* Mentee Two

The NHS would also have access to patients at the right time and have the specialist knowledge and resources for safeguarding and support:

> *"It would have to be somebody who's got real experience of brain injury. The [local] brain injury team has a counsellor, occupational therapists, case workers."* Mentor Four

The mentors said that NHS rehabilitation services could work with brain injury charities, such as Headway and the Stroke Association, in order to provide more options and greater access to peer mentoring:

> *"But, at the same time, if people are at Headway, then we could offer support there as well. It's important to be part of both, but then at Headway it could be like a volunteer kind of thing*." Mentor One

5.7.2 Healthcare Professional Interviews

I interviewed five healthcare professionals who were rehabilitation providers at the recruitment sites. The interviews focussed on the interviewees' professional opinions about the value of peer mentoring and the issues involved with recruitment for the project. The findings were grouped into four main themes:

Theme One: Attributes of Peer Mentoring

Theme Two: Recruitment Issues—Patients

Theme Three: Recruitment Issues—Clinicians

Theme Four: Peer Mentoring Providers

Each theme (with the exception of Theme Four) encompasses several recurring sub-themes. Definitions of these sub-themes, their connections to the ICF and BCW, and example quotes are provided in Appendix 14.

Theme One: Attributes of Peer Mentoring

This theme concerned the advantages and disadvantages which the healthcare professionals attributed to peer mentoring, particularly in relation to other rehabilitation interventions. The following five recurring sub-themes were grouped under this heading: 1) shared experience; 2) impartiality; 3) individualised support; 4) social and leisure participation: and 5) potentially negative influences.

Shared Experience

The clinicians were positive about the concept of peer mentoring and believed that it had enormous potential:

> *"I think it would be a really good thing. I really think it's really positive and I think it can be really powerful for patients."* HCP Three

They thought that support from someone with shared experience offers something different and important which clinical interventions do not:

> *"In principle, I like the idea of it, and I can certainly see that, you know, speaking to somebody who's been through a shared experience would be beneficial."* HCP Five

One interviewee said that a mentor could act as a guide through recovery and would be important for showing the mentee that the way they feel is normal:

> *"And you often say what they need is either a good friend, or like a mentor, someone who can take them under their wing and say you're not going crazy. You know, and sort of guide them through the journey."* HCP 4

Impartiality

The clinicians said that peer mentors have the benefit of being non-threatening, non-judgemental, and unconnected to recovery goals and targets. Therefore, the patient would be able to relax and not feel like they have to prove anything:

> *"Hopefully you know non-threatening support, and hopefully they feel like they're not being judged. I definitely think there could be a lot of positives to that…hopefully there's a lot of value in just talking to somebody without them actually assessing you or wanting you to do anything or provide an outcome."* HCP One

Emotional support and an impartial listening ear were thought to complement the traditional aspects of rehabilitation:

> *"The peer mentoring it might just be around providing that more emotional support, and just someone to talk about what's going on. Not necessarily to like push you to achieve something or not achieve something."* HCP Two

An impartial person offers the patient the opportunity to be honest, share their feelings and say things they might not be comfortable saying to a close family member or friend:

> *"I think sometimes they just need somebody to speak to who is not involved. Because sometimes relatives are too close and the patient doesn't want to tell them because they don't want to upset them. Sometimes professionals, they think, 'it's just a job to you', spouting medical jargon."* HCP Four

Individualised Support

The HCPs said that peer mentoring could focus on the specific needs of each person. One-to-one support offers this advantage over some other forms of rehabilitation and group support:

> *"Some people are better in a group, some people would be terrible in a group…Because if you've got aphasia or expressive/receptive issues you might struggle in a loud cafe. In a one to one with somebody, you might be able to get much better quality of contact."* HCP Two

One-to-one peer support also offers the opportunity to engage in activities the person specifically enjoys:

> *"If you've…somebody like 'well we want to go for a game of golf or go to the cinema', you've got more scope to do those individualised things rather than a group."* HCP Two

Social and Leisure Participation

Peer mentoring can help people to increase their participation in social and leisure activities, which can be difficult for rehabilitation services to help with:

> *"Social inclusion and community activity doesn't come to the top of the list with statutory rehab services. So it could certainly supplement what people are offered…taking people out for coffees and getting to the gym and getting them swimming and building their confidence to walk outside."* HCP Five

A strength of mentoring is that it can help people plan ways forward and work towards specific, individual social and leisure goals:

> *"Someone to bounce ideas off and meet and help them, maybe or work on their community access… I would say like quality of life…and engagement and amount of activity they're doing."* HCP Two

Mentoring was considered to be a potentially powerful way to build a person's social confidence, particularly young patients:

> *"Some of the younger ones that we could do with being more active and more engaged, it might help with that…That skill to put themselves out*

there…so improving confidence to go out to socialise, to just have that community access and social skills in a different situation." HCP Three

Potentially Negative Influences

Some participants thought that some peer mentors could potentially have a negative influence. For example, having not themselves attained goals aspired to by the mentee:

"Could have an impact on how the mentee's feeling. So, for example, if the mentee is really driven to go back to work and they have a mentor that says, oh I'm doing alright but I've never made it back to work…" HCP One

Another interviewee said that a mentor who still has severe impairments a long time after their injury could cause anxiety for a mentee in the early stages of recovery:

"Being paired with someone that's still severely impaired 10 years down the line, yeah, I can see how that would freak people out…[some] people think oh that could be me. I might stay in this state." HCP Five

Theme Two: Recruitment Issues—Patients

Themes Two and Three both incorporate issues relating to the recruitment of participants. Theme Two includes issues pertaining to the clients themselves and comprises six related sub-themes: 1) behavioural issues; 2) physical issues; 3) cognitive issues; 4) insight and acceptance of condition; 5) time since hospital discharge; and 6) lack of willingness to participate.

Behavioural Issues

All the HCPs were concerned about referring clients with behavioural issues, such as anger and inappropriate behaviour, which might cause problems in one-to-one, unsupervised meetings in the community. The safety of mentees and mentors was of primary concern:

> *"Are they a safe person to match with somebody else and leave on their own to do that and can they be managed or have they got, you know, behavioural issues, anger issues…"* HCP Two

These concerns prevented clinicians from referring some clients even if they thought they would benefit from participation:

> *"There were ones we thought would benefit, but like you say sometimes some of the patients could be a bit inappropriate, insensitive, like inappropriate touching and things like that."* HCP Four

Physical Issues

Patients' physical impairments were reported to be a significant concern when considering referrals. The clinicians were reticent about referring people with physical impairments which might prevent them from safely getting to and from meetings:

> *"…physically can they get there because if you're asking people to meet people can they actually get somewhere safely so can they leave the house, safely."* HCP Two

They also expressed concerns about placing an unfair burden on a mentor and expecting them to help the mentee physically with movement:

"You want to be inclusive don't you but for the mentor you'd have to think about moving and handling. And do you want to go down that route." HCP Four

Cognitive Issues

The cognitive effects of brain injury, such as memory, attention, and concentration problems, were considered to be barriers to participation in peer mentoring. One reason for this was the requirements of organising, remembering, and travelling to meetings:

"…can they organize themselves safely not get lost on the way to somewhere, you know, so those safety things would be high in your mind." HCP Two

One interviewee said that a worry with referring people to any service was about potentially overloading them. The clinician worried whether a patient could cope with extra commitments:

"They might already be having appointments with speech therapy, occupational therapy, a case manager…solicitors and it's kind of a juggling act of how much they can cope with at that one time and the peer mentoring is almost another thing thrown into that." HCP One

Another issue was balancing the cognitive demands of multiple appointments with sometimes chaotic home environments:

"There were a few people's social situations that made me question if it was probably the right time for them and they're more your sort of chaotic, are they going to remember to do this, are they going to follow up on it, are they going to participate?" HCP Five

However, it was also pointed out that peer mentoring can be more suitable for some people with cognitive impairments than other forms of therapy, such as group support. This is because group settings can be overwhelming:

> *"Attention issues, memory issues, cognitive issues too, the idea of a one-to-one option rather than a group setting would be… that would be better."* HCP Two

Insight and Acceptance of Condition

Adequate insight and self-awareness were considered to be necessary requirements for referral:

> *"Where I would be concerned is about their level of insight. That would make me kind of consider whether or not they would have been appropriate."* HCP Three

One reason for this is so that people can understand their impairments and work towards realistic goals:

> *"So, they've got to have a level of awareness and insight. People have got to be willing to sort of change and listen."* HCP Four

Lack of acceptance of the injury often means that people do not wish to identify as a brain injury survivor. This is a reason cited by interviewees for patients not wanting to engage with other people with brain injuries:

> *"Sometimes people aren't accepting and they don't want to acknowledge they are like other people like that. For some people, it's almost like a coping mechanism that they've got the hope that they're going to get back to how they were."* HCP One

Another problem arising from lack of insight is overestimating one's own abilities and taking on too much as a result. One interviewee expressed wariness about referring people with these issues to projects such as this:

> *"So, there are some people that if I'm honest, they might have met the criteria and they might have deemed it was something that they could manage. But if that isn't a realistic expectation that is something that could then run into difficulties with. So, because of their insight into their abilities, overestimating what they can do in terms of either time and commitment, or organisational management."* HCP One

Time Since Hospital Discharge

Some patients fitting the project's criterion of less than twelve months post-discharge were not considered ready for peer mentoring:

> *"When I think about some of the current caseload, perhaps, by the time they're sort of ready to engage as a mentee I wonder if they're then past that twelve months post-discharge."* HCP Three

Clinicians suggested that this criterion could be changed for future mentoring projects because it might rule out some people who could benefit from a mentor. One interviewee suggested that there could be no time limit, as the most important thing is for people to access the service when it is right for them:

> *"Just because you had a stroke six months ago doesn't mean you couldn't access a mentor at two years post-stroke, that might be the right timing for you. And so you don't want a service which is time limited."* HCP Two

Lack of Willingness to Participate

The clinicians said that patients can be unwilling to engage with services such as peer mentoring due to insufficient interest or motivation:

> *"I think on a one-to-one you say they're running this study, are you interested, they say oh yeah I'm dead up for that. But, actually, when it comes to sitting down and reading things and giving consent, it goes [indicates overhead]."* HCP Five

The idea of participating in peer mentoring can be quite daunting for many people with a brain injury, who may have problems coping with stress, anxiety, and novel situations:

> *"I think it'd be quite anxiety provoking. And, you know, anxiety, depression, all the things that would benefit from some peer support would be a barrier to them actually participating in the first place."* HCP Five

One suggestion to enhance engagement was to provide easy-to-use, online information and consent materials:

> *"Whether you could do more like online. That's something more that a clinician could sit with them and say, 'Actually we're here and we've got this half an hour in clinic I wanted to talk to you about this study'. I think you'd have a lot more recruitment uptake if people had that time to just sit and run through it."* HCP Five

Finally, other priorities in clients' lives could affect their availability and willingness to take on other commitments, especially potential mentors:

> *"For the people that almost would have been quite good mentors, the problem is some of those then are back at work, and again whether or not the employer would have released them to do that or whether or not they could have managed it on top of work."* HCP Five

Theme Three: Recruitment Issues—Clinicians

This topic pertains to factors related to the recruiters themselves and their capacity and willingness to refer clients to the project. This comprises four recurring sub-themes: 1) referral to an external project; 2) client availability; 3) clinician judgements; and 4) clinician engagement.

Referral to an External Project

Some interviewees referred to the unwillingness of themselves or other professionals to refer clients to research projects outside of their own service. Several HCPs said that this is a potential barrier to recruitment, and one said that she had some reservations over this project:

> *"I was a bit unsure. I know there were sort of support mechanisms in place, but how much clinical input there was from, for example, psychologists or people if issues came up."* HCP One

Conversely, other interviewees expressed their confidence in the project and stated that referring clients to external services such as this was important:

> *"That doesn't concern me. Because we access a whole range of things for patients, like work and Headway and so there's plenty of sort of services you perhaps tap into that, they're out of your control once you've kind of sent them on if you like. And no that that's not a concern."* HCP Three

One clinician stated that she and her team took a liberal approach and had no reservations about referring clients. However, she also said that other services were more cautious:

> *"I think some of the teams are a bit like, 'ooh can we trust you to do that kind of work'. They'd be a bit worried about recommending it if something went wrong, the mentor said the wrong thing, misled them, that probably would put some professionals off referring."* HCP Four

Client Availability

A key limiting factor for recruitment was the number of clients available. The recruitment sites had low numbers of clients matching the eligibility criteria, partly because they tended not to treat people soon after their injuries:

> *"I don't think we had that many at all, because our referrals are quite staggered…so it's not like as a service we get loads of new referrals each week."* HCP One

Another service had a high proportion of people with long-term, severe injuries who would not have been suitable:

> *"A big chunk of our caseload wouldn't sort of fit the criteria. In terms of, you know, they're in slow stream rehab they've probably got limited communication, limited understanding."* HCP Five

Clinician Judgements

Three of the interviewees acknowledged that they made judgements about the suitability of patients, which may have omitted people who could have benefitted. They also said that it might have been better to refer them:

> *"Maybe as clinicians rightly or wrongly we're maybe making a judgement on…can they sort of take on something at that time?"* HCP One

This was done with the best interests of the patients in mind, with consideration for what they were able to do:

> *"You don't want to overwhelm them. I think we're so aware of what people are going through that I think probably a few times we maybe thought 'no they're just not in that space' and you know what, maybe that wasn't my decision to make."* HCP Five

The HCPs conceded that they may have a tendency towards 'overprotectiveness'. They suggested that their own judgement could be removed from the equation in order to select everybody who meets the inclusion criteria:

> *"I think it would be interesting to just go through the caseload at the time and not think about the person, just think about time post-injury, does the diagnosis and time fit the criteria."* HCP Three

Another interviewee suggested removing the treatment team from the referral process entirely and allowing people to self-refer as mentees:

> *"I suppose, we've got a duty of care to our clients so that's the difficult thing...And if they'd been able to just sort of self-sign up to the study, that could have been explored I suppose."* HCP One

Clinician Engagement

All the interviewees said that they actively engaged with the project and discussed it among their teams:

> *"I think we did it quite regularly. It came up in our team meeting minutes, and we regularly came back to research and talked about it."* HCP Two

However, maintaining engagement over time was acknowledged to be an issue. One interviewee stated that after a while the project became a lower priority and there was less effort to identify patients, which could have hampered recruitment:

> *"I don't know whether towards the end of your recruitment period, whether it may have dropped off the radar."* HCP Two

The researcher's role in providing regular reminders and prompts was mentioned as being important for maintaining engagement:

> *"I have to say you did prompt us on occasion. Give us a reminder to think again. And we would certainly go through the caseload and then at that point sometimes that's when it would prompt us."* HCP One

It was suggested that a researcher situated within the clinical team, who is dedicated to participant identification, would facilitate much greater recruitment:

> *"If you're fully* funded, *you might be able to access somebody who can really, you know, look and push, push people to be recruited. You've got*

to have someone in there inside the team pushing our team to keep recruiting." HCP Two

Another interviewee emphasised the importance of clinicians and researchers working as hard as possible to push for referrals, talking to patients and recruitment staff, and providing as much information as possible:

"We could sell it a bit more. Maybe we could ask during the first face-to-face interview. To sow the seed early on. Maybe you could come to a team-leaders meeting and sell yourself there." HCP Four

Theme Four: Peer Mentoring Providers

Interviewees were asked which service providers are best able to deliver peer mentoring and how peer mentoring should fit with other forms of rehabilitation. None of the clinicians felt that NHS rehabilitation services, such as their own, should have exclusive ownership of peer mentoring:

"I don't necessarily feel strongly that it needs to be managed 'in house' as such. I think it could work in collaboration [with other providers]." HCP One

Clinicians recognised the limitations imposed by situating the service within one organisation, and the advantages of a standalone service:

"If you embed it into, say, our stroke service, your peer mentoring will be curtailed by the fact that we only see people for a year. So, if you embed it within a certain service, you might have limitations on whatever service you embed it in. So, I suppose if it stands alone, that you don't get those limitations." HCP Two

One interviewee stated that key aspects of a peer mentoring intervention, such as recruitment and safeguarding, would have to be provided by clinical rehabilitation services:

> *"I think if it was a completely standalone project, it would, excuse the French, but fall on its arse. Because you haven't got an infrastructure for: a) getting your referrals in; and b) somewhere to go to manage those concerns and have the advice."* HCP Five

If the support was in place, then non-medical providers, such as charities, social services, or researchers, could help to provide mentoring:

> *"I think like a combination would be ideal. So, you could have regular supervision with us. That might be a good way of monitoring it, regular supervisions. It'd be good for yourself to offload."* HCP Four

Participants said that an advantage of linking different services together to run peer mentoring would be to make it available to a wide range of people as and when they need it, at any stage of recovery, and no matter what service they are currently involved with:

> *"Embedded I think, and across the whole service, because you could use it right across and it wouldn't matter in terms of timing, in terms of the service. It becomes part of that so you can consider that at any point across rehab."* HCP Three

5.8 Data Synthesis

The quantitative and qualitative data are summarised and synthesised in Table 5.31. The data are evaluated for complementarity and/or contradiction.

Synthesis is presented in the final column. The synthesis reveals patterns of both complementarity and contradiction across the main study outcomes.

Table 5.24. Data synthesis.

Main outcomes	Quantitative data	Qualitative data	Integrated findings
Feasibility: Recruitment and Sample Characteristics	Twenty mentors applied, twelve participated in training, and nine completed training. Four participated in the intervention (four female, age range 30-49). Recruitment took six months. Twenty-one potential mentees were identified, four were ineligible, and eleven withdrew interest. Six consented, of whom two withdrew before the intervention. Four participated in the intervention (three female, one male, age range 51–79). Recruitment took ten months. Three carers and five recruiters participated in qualitive interviews.	*Recruitment issues–patients:* Clinicians may be unwilling to refer patients with physical, cognitive, and behavioural problems. The first 12 months after injury might be too early to become a mentee. Concerns about overloading patients who are already receiving treatment from multiple services. Some patients are unwilling to commit to mentoring. *Recruitment issues–clinicians:* Clinicians can be overprotective of patients and unwilling to subject them to perceived risk. They made judgements about a client's suitability, despite them meeting the eligibility criteria. Many services do not have sufficient numbers of eligible clients. Healthcare professionals are very busy and recruitment for research projects is not a high priority, so over time their engagement with recruitment diminishes.	<u>Some complementarity and some contradiction.</u> The quantitative data showed that it was difficult to recruit for this project. The qualitative data provided some possible explanations for this.
Feasibility: Data Collection	All the participants completed all the items on the questionnaires. There were no missing data. Each questionnaire was completed in a few minutes and no participants required a break or reported any difficulties. All the questionnaires were completed face-to-face or by telephone. All the participants completed all sections of the qualitative interviews, with no breaks required. One mentor was unable to take part in the post-intervention qualitative interview, while one carer declined to participate in the interview. The only large change observed in the group means was for mentees on the Home Integration sub-scale of the CIQ. Most other changes were small, with CIs which suggested chance results. On an	The process of data collection was not addressed in the qualitative interviews. All the quantitative assessments were completed quickly and without difficulty. There were no instances of participants struggling with any questions or becoming upset. Indeed, the participant with severe aphasia was able to complete all the questionnaires easily by indicating the correct response. The themes arising from the qualitative interviews did not correspond extensively to the concepts underlying the quantitative measures. This suggests that either the quantitative measures did not fully address outcomes that were	<u>Complementarity</u> All the information points to the acceptability of the data collection procedures, the usability of the measures used, the length of the assessments and interviews, and the qualitative topic guide questions. Although individual level changes indicate the sensitivity of the measures, there were no changes in the group means. The qualitative data did not highlight issues with quality of life, hope for the future, mood, and carer burden. However, the qualitative topic guides

Main outcomes	Quantitative data	Qualitative data	Integrated findings
	individual level, the measures detected changes which indicated their sensitivity.	important to participants, or that the qualitative topic guides did not sufficiently enquire about the outcomes addressed by the quantitative measures.	may not have adequately addressed these constructs.
Feasibility: Acceptability	*PMQ–Satisfaction with Programme* The PMQ responses indicated high levels of satisfaction with the mentors and with the number, duration, and frequency of meetings. *Training* The training days were delivered as planned, with no problems. The training evaluation forms indicated high levels of satisfaction with the content of the training. *Intervention* Two pairings completed all seven meetings, one had three meetings, and one had two (including the introductory meeting with me present). Two mentees withdrew before completing their quota of meetings. There were no adverse events.	*Mentor Training Evaluation:* Free text responses on evaluation forms showed that participants found the topics and activities useful, relevant and interesting. The training was considered to be beneficial and successful in preparing participants for the mentoring roles. *Practical Issues for Meetings and Activities:* The qualitative interviews showed that there were numerous difficulties with arranging and attending meetings. Physical impairments made travel difficult and prevented people from wanting to take part in activities. There were some communication difficulties between pairs, including misunderstandings and inability to contact each other. It was often difficult to find mutually convenient times to meet due to conflicting arrangements and other commitments. *Benefits of Peer Mentoring:* The qualitative interviews showed that the mentors and one mentee, derived great benefit and enjoyment from their involvement. However, three of the mentees reported that they did not, overall, derive much benefit from the intervention. *Training and Support Needs of Participants* In the qualitative interviews, the mentors reported enjoying the training days and finding them extremely useful to prepare them to be mentors. The help and support from the researcher was said by the mentors and the carer of one mentee to be extremely	<u>Complementarity, but with some contradiction.</u> The quantitative evaluations of the training corroborated the qualitative reports from mentors and my own experience. The sessions were enjoyable for all, useful and helped to prepare the mentors for their role. The quantitative assessments of the intervention suggested high levels of satisfaction, but the qualitative interviews showed that three mentees were not satisfied. The reasons for this included lack of compatibility with the mentors, frustration with the time from recruitment to starting the intervention, and difficulties with arranging meetings. However, one mentee, one carer, and all four mentors enjoyed their participation and felt they benefitted from it.

Main outcomes	Quantitative data	Qualitative data	Integrated findings
		useful and reassuring. However, the two mentees who ended their partnerships early, and one of their carers, suggested that they did not feel the communication with the researcher helped them. *Suitability and Compatibility* Three mentees did not feel that their mentor was well suited to them, mainly due to their different types of injury and experiences of recovery. This conflicted with the views of mentors, who felt that the differences in their experiences were outweighed by the similarities. Two of those mentees reported liking and getting on well with their mentor, but one did not feel that their mentor's personality was compatible with their own. One carer said that the mentor was a perfect match with his mother, despite the differences in injury, experience and age.	
Feasibility: Resources and Management Capability	There were several delays to obtaining ethical approvals and the lack of referrals meant that recruitment took longer than planned. Recruitment required time and resources to meet with the different clinical teams and to maintain their engagement. Mentor training required significant time to plan, prepare and organise. Expenses were incurred in staff time and travel costs. It was necessary to travel to participants homes to conduct assessments. This incurred time and travel costs. Supporting and monitoring the participants during the intervention was time consuming.	From a personal perspective, the project was challenging to operate as a lone researcher.	<u>Complementarity.</u> The quantitative information regarding the number and length of delays and application refusals, recruitment problems, and logistical requirements are reflected in my own qualitative experience of the project. For a small project, there are many threads to be managed simultaneously and there are significant resource requirements.
Participation	**Mentees:** CIQ group mean: Baseline–17.63; post-intervention–16.88. CIQ Home Integration group mean: Baseline–6.88; post-intervention–4.38.	*Practical Issues for Meetings and Activities:* Activities were restricted to travelling to meetings, talking, and some walking. Physical impairments and motivation were said to have prevented people	<u>Complementarity/some contradiction</u> There were no clear improvements on the quantitative measures of participation and the qualitative interviews showed that participants were satisfied

Main outcomes	Quantitative data	Qualitative data	Integrated findings
	CIQ Social Integration group mean: Baseline–9; post-intervention–10. CIQ Productivity: Baseline–1.75; post-intervention–2.5. All four mentees decreased on Home Integration; three improved and one decreased on Social Integration; two improved and one decreased on Productivity; one improved and three decreased overall. Goals achieved: Reason to get out more; meeting people; going for walks. Goals not achieved: Going shopping; increasing social activities. **Mentors:** CIQ group mean: Baseline–20.5; post-intervention–20.75. CIQ Home Integration group mean: Baseline–6.00; post-intervention–6.25. CIQ Social Integration group mean: Baseline–9.5; post-intervention–9.5. CIQ Productivity group mean: Baseline–5; post-intervention–5. Three mentors remained unchanged for the CIQ Total score and for each sub-scale. One mentor increased by 1.00 from 5.00 to 6.00 on the Home Integration sub-scale. Goals achieved: meeting new people; getting out and doing something different; meeting other people with brain injuries. ***PMQ–Social Support*** The majority of mentors and mentees did not consider mentoring useful for improving social support.	considering more ambitious or varied activities. *Benefits of Peer Mentoring:* Participants of all kinds reported that talking to a mentor was beneficial for mentees, while the mentors themselves benefitted from meeting and talking with people with shared experience. *Healthcare providers: Social and Leisure Participation* Healthcare provider interviewees said that enhancing social and leisure participation should be a key outcome for peer mentoring. This is because of the potential it offers for focusing on individual interests and because clinical rehabilitation services are limited in the help they can provide in this area.	with meeting to talk, rather than planning other activities. Several participants achieved their participation-related goals and several talked about the value of going out and interacting socially with their mentor/mentee. This suggest benefits which were not shown by the CIQ.
Mood	**Mentees:** DASS-21 depression group mean: Baseline 4.50; post-intervention 5.50. DASS-21 anxiety group mean: Baseline–3.00; post-intervention–8.50. DASS-21 stress group mean: Baseline–11.00; post-intervention–14.00.	The impact on mood was not directly referred to in the qualitative interviews. However, some mentors did refer to the sense of satisfaction and boost in self-esteem that mentoring gave them. The healthcare professionals said that emotional support and enhancing self-esteem were important goals of mentoring.	<u>Some contradiction</u> There were some contradictory findings in the quantitative sources. The PMQ responses suggested that mentoring had a positive impact on mentees' mood, but this was not reflected in the DASS-21 results. Two mentees showed large deteriorations on the DASS-21, which were not

Main outcomes	Quantitative data	Qualitative data	Integrated findings
	Mentee Two increased from 8 to 16 for depression, 10 to 16 for anxiety, and 24 to 28 for stress. Mentee Five increased from 2 to 18 for anxiety and from 14 to 26 for stress. There was little or no change for the other mentees on all scales. **Mentors:** DASS-21 depression group mean: Baseline–3.5; post-intervention–4.5. DASS-21 anxiety group mean: Baseline–1.00; post-intervention–1.50. DASS-21 stress group mean: Baseline–12.00; post-intervention–13.50. All changes for individuals were small. *PMQ–Mood:* The majority of participants said that mentoring was helpful for the mentees' amount of happiness, amount of sadness/depression and amount of anxiety. The majority said it was of no help for amount of anger. *PMQ–Emotional Adjustment:* The majority of participants said that mentoring was no help for the mentees' feeling of belonging or learning about emotional distress. Most people said it was helpful for decreasing feelings of being alone.		explained in the qualitative data. Some deteriorations on the DASS-21 anxiety scale were also contradicted by the EQ-5D-5L anxiety scale. The mentors' positive reports about benefitting from the intervention were not reflected in the DASS-21 scores, but this is not unexpected because the baseline scores were already low, with small margins for improvements.
Quality of Life	**Mentees:** EQ-5D-5L Index mean score: Baseline–0.44; post-intervention–0.39. Visual Analogue Scale mean score: Baseline–76.88; post-intervention–72.50. There were only small changes for individuals, all of which were within the expected margins of chance. **Mentors:** EQ-5D-5L Index mean score: Baseline–0.33; post-intervention–0.37. Visual Analogue Scale mean score: Baseline–77.75; post-intervention–75.75.	*Benefits of Peer Mentoring:* The experience of participating in the project, having a purpose, meeting people, and having something to do, was described in terms that suggested it enhanced quality of life for some participants, at least for the duration of their involvement. This applied particularly to mentors and to Mentee Three. *Healthcare providers: Attributes of peer mentoring:* Healthcare providers did not refer specifically to QOL but did refer to the life-enhancing potential of peer mentoring. They talk about making a person feel understood, less alone, and helping them to	<u>Complementarity</u> There was very little quantifiable difference in quality of life. The interviews suggested some impact, mainly on the self-esteem of mentors. The PMQ-Empowerment results also suggested some impact on mentees' overall quality of life and ability to deal with life, complementing the qualitative data.

Main outcomes	Quantitative data	Qualitative data	Integrated findings
	There were only small changes for individuals, within the expected margins of chance. *PMQ–Empowerment and Quality of Life* The majority of participants said that mentoring was helpful for the mentees' ability to deal with life and overall quality of life. The majority did not think it was any help for the mentees' control over life.	participate in enjoyable activities, all of which enhance QOL.	
Hope for the Future	**Mentees:** Herth Hope Index group mean: Baseline–42.0; post-intervention–42.0. Mentees Two and Five both scored lower post-intervention than at baseline, while Mentee Three improved by 5.00 from 38 to 43 and Mentee Six remained unchanged. **Mentors:** Herth Hope Index group mean: Baseline–40.00; post-intervention–41.25. Mentors Two and Three improved post-intervention, while Mentors One and Four remained unchanged.	*Benefits of Peer Mentoring (mentees, mentors and carers) and Attributes of Peer Mentoring (healthcare providers):* Participants referred to mentoring as helping to facilitate a positive attitude to recovery and life with the injury, thereby helping to provide hope for a future with the injury. However, healthcare providers also said that there could be a negative impact of seeing a mentor who still has issues, thereby provoking a fearful view of future with the injury.	Unclear There were no clear quantitative changes and the qualitative interviews only obliquely addressed the topic in terms of facilitating a positive attitude to recovery. No mentees specifically mentioned hope for the future. There was no evidence that mentoring had a negative impact, contrary to the view of some healthcare providers that this could be the case for some people.
Carer Burden	Caregiver Burden Scale group mean: Baseline–20.00; post-intervention–16.67. All three carers improved.	Carers were not asked about the impact on their perceived burden and did not specifically refer to themselves in relation to it. However, Carer One was very positive about the project and said that having someone else help his mother relieved some of the pressure on him.	Unclear The quantitative results showed a positive impact on carer burden. However, carers in the interviews did not specifically address the topic. It is reasonable to suggest that the intervention reduced the burden experienced by Carer One, at least for the duration of the project.

5.9 Discussion

I set out to develop a peer mentoring intervention for people with ABI, drawing on the findings of the systematic review, PPIE work, and qualitative interviews with stakeholders to create an acceptable design to target key outcomes. The

study of the peer mentoring intervention went a long way towards finding out whether it is really feasible. The model was based on pairs meeting independently, in the community, six times over approximately three months, and talking and engaging in enjoyable activities. Some aspects worked well, but many were not as successful as expected. However, by developing, piloting, and evaluating a model designed in accordance with the MRC Framework (Skivington et al., 2021), the study has made a valuable contribution to knowledge in the field.

The study was unquestionably challenging and a larger study employing the same methods is considered unfeasible. The recruitment of mentees was particularly difficult, with only six consenting to take part, two of whom withdrew prior to matching. Suitable mentors proved easier to recruit and twelve people participated in the mentor training programme, with nine completing the training and consenting to become mentors. Four pairs were matched and supported to engage in seven peer mentoring sessions each over twelve weeks (including one introductory meeting); however, only two pairs completed all the sessions, while one pair completed three meetings, and one pair met just twice.

Outcomes were collected on measures of participation, mood, quality of life, and hope for the future. These measures showed sensitivity, with some interesting changes for individuals, but there were no clear patterns of change for the groups. The results for mentors showed that they had reached a point of stability in their recovery, had low impairment levels, achieved their goals and qualitatively reported positive experiences. One mentee and her carer reported a hugely positive experience. However, three mentees reported disappointing

experiences of mentoring, mainly related to dissatisfaction with matching and the challenges of organising meetings.

Feasibility

Recruiting mentees was particularly challenging, as previous studies have also discovered, both in the UK and other countries (Hibbard et al., 2002; Struchen et al., 2011; Masterson-Algar et al., 2020; Levy et al., 2021). I recruited mentees from all the relevant sites in the catchment area, but only six people consented to take part and two withdrew. Had I been able to match the other two to mentors quickly then they may have participated, but the delay finding suitable matches meant that their circumstances changed and they lost interest in participating. In the interviews, the recruiters provided several reasons for the challenges of recruiting mentees, including a cautious approach to referring patients they did not to be consider ready or able, lack of eligible patients, lack of motivation from patients, and loss of engagement with the project from staff. Mentors were more forthcoming, but still only nine consented to participate. Recruiting enough suitable mentors has also proved difficult in previous peer mentoring studies (Hibbard et al., 2002; Struchen et al., 2011; Masterson-Algar et al., 2020; Levy et al., 2021).

The training days were delivered as planned, with no problems. This part of the study built on the training content and methods used in previous studies, replicating the success of those studies and potentially improving on the content of the training (Struchen et al., 2011; Hanks et al., 2012; Kersten et al., 2018). The positive quantitative evaluations of the training corroborate the mentors' qualitative reports and my own experience. Although there were

improvements that could be made to the training in future, the mentors found the sessions enjoyable, useful, and helpful in preparing them for their roles. Three participants were unable to attend some or all of the sessions and, unfortunately, time and resources did not allow for further face-to-face training. Instead, I discussed the training content with the participants on the telephone, adapted some of the activities for this medium, and sent them slides and handouts by email. This was well received and useful, but did not sufficiently replicate the full days of training. Of the three people who withdrew from the study after taking part in some or all of the training, two stated that the training helped them to realise that they were not ready to be mentors because they did not feel they had sufficiently come to terms with the effects of their injuries. This is an interesting finding and indicates the effectiveness of the training in demonstrating the qualities required of a mentor.

One of the goals of the intervention design was to encourage participation in activities. However, the activities mainly involved meeting in coffee shops to talk, along with some brief walks around shopping areas near the coffee shop locations. There were no adverse events, but there were numerous difficulties with arranging and attending meetings. Physical impairments made travel difficult and prevented people from wanting to take part in activities. There were some communication difficulties between pairs, including misunderstandings and inability to contact each other. It was often difficult to find mutually convenient times to meet, due to conflicting arrangements and other commitments, and the effort required to maintain involvement in the project led to two mentees ending their partnerships early. These findings are

reminiscent of a peer coaching after stroke project, operated in Wales in 2015, in which only one pair met the required six times (Masterson-Algar et al., 2020).

The delays and difficulties with the ethics application process were challenging and addressing the requirements of the sponsors and ethics committees was time consuming. The different threads of the project were also challenging to operate as a lone researcher and required considerable time and resources. For example, the mentor training required a lot of planning and organisation from myself, a divisional administrator, a colleague to help run the sessions, supervisors to review plans and training content, and university colleagues to attend practice sessions. There was also expense involved with catering and participants' travel costs. Travelling to participants homes to conduct assessments, and travelling to introductory meetings between pairs, was also time consuming and costly.

Managing the partnerships during the intervention period was also challenging and resource intensive. Participants forgot to call or text me before and after meetings on almost every occasion, so it was necessary to contact them, often repeatedly due to them not responding. It was necessary to keep track of meeting times and venues, maintain regular contact with participants to monitor progress, discuss problems with organising meetings, and encourage them to make arrangements. Other studies have reported similar challenges with the resources required for peer mentoring projects (Kessler et al., 2014; Masterson-Algar et al., 2020; Levy et al., 2021). Although manageable, the time, costs, and staffing resource implications would need to be considered for any larger project, especially regarding recruitment.

Main Quantitative Findings

The standardised measures gave no clear indications of improvements for either mentees or mentors, with no change for most mentors across the measures. Other studies have also reported little or no quantitative change after mentoring on measures of participation, including the CIQ (Hibbard et al., 2002; Hanks et al., 2012; Struchen et al., 2011; Kolakowsky-Hayner et al., 2012; Hilari et al., 2021; Levy et al., 2021). However, there were some negative changes worthy of note for mentees. The clearest sign of change was a deterioration for mentees on the Home Integration sub-scale of the Community Integration Questionnaire. All four mentees deteriorated, while the post-intervention group mean was markedly reduced from baseline. The items on this scale ask who in the respondent's home shops for groceries, prepares meals, does housework, cares for children, and plans social arrangements, with two points for yourself alone, one for yourself and someone else, and zero for someone else.

The poorer scores indicate that the mentees were receiving more help with tasks at home than they were prior to the intervention. One interpretation of this is that the mentees had become less independent and required more help at home. Another interpretation is that mentees had become more aware of their difficulties and of the tasks they required help with and were asking people for help more. Friends and relatives may also have become more aware of the help that the mentees needed and were helping more than previously. However, the mentees also all showed small improvements on the Social Integration and Productivity subscales, suggesting that their participation levels had improved away from the home and that they had less time for home tasks. It is difficult to

say whether the intervention had an influence on these changes or whether they were simply the result of natural progression and adaptation to the mentees' injuries. One mentee had returned to work, which would have meant having less time for tasks at home and could explain their changes in the outcome measures.

The scores for two mentees deteriorated on the DASS-21 depression, anxiety, and stress subscales. These changes could be attributable to changes in the mentees' lives unrelated to mentoring; for example, Mentee Five returned to employment during the intervention, which has been shown to cause stress and anxiety, particularly for people with brain injuries (Phillips et al., 2019; Radford et al., 2018). Alternatively, the changes could be due to increased awareness of brain injury-related impairments, which could have been brought about by interactions with the mentor and the self-reflection encouraged by the intervention. Struchen et al. also reported similar increases in depressive symptoms among mentees and suggested that increased self-awareness and insight could explain the findings (Struchen et al., 2011). However, other peer mentoring studies have found little or no significant change on measures of mood (Hanks et al., 2012; Levy et al., 2021). The responsibilities and pressures of taking part in the intervention and being expected to arrange and attend meetings may have had an influence on the changes in outcome scores. However, it is worth noting that the DASS-21 asks about symptoms over the previous week and the post-intervention assessments took place several weeks after the intervention concluded. The changes in these areas could have been due to increased awareness of difficulties and their long-term nature which were unrelated to the intervention and are a natural element of recovery from

brain injuries. Some of the changes may also be attributable simply to issues arising in the mentees lives in the previous week. It was encouraging to find no increases for the mentors, suggesting that the pressures of mentoring did not have a detrimental effect.

The use of the Peer Mentoring Questionnaire provided further insights which suggested improvements that the standardised measures did not detect. For example, most participants, including some mentees, said mentoring was helpful for the mentees' ability to deal with life, overall quality of life, and decreasing feelings of being alone. Hibbard et al. also found self-reported impacts on the ability to deal with life and overall quality of life among mentees using this questionnaire (Hibbard et al., 2002).

The improvements for all three carers on the Caregiver Burden Scale suggest that the intervention may have had a positive impact on carer burden. This could be due to the mentors relieving some of the burden. It could also be due to the burden easing naturally over time as the mentees have adapted to their injuries and become more independent. Furthermore, the perceived burden of caring can naturally fluctuate along with other factors in the lives of the mentees and carers. Other people may have started providing more support as time has passed, and pressures may have eased in other areas of the carers' lives, meaning that caring for the mentees is less stressful. Hibbard et al. also found some impact on family members of TBI mentees on their ability to cope with life, overall quality of life, and depression (Hibbard et al., 2002). There has been very little other research into the impact of mentoring on the carers/family members of mentees, so this is a promising area for larger scale investigation.

Main Qualitative Findings

It was clear from the interviews that the mentors were considerably more positive about mentoring than the mentees. It was also clear that all the participants could see considerable potential benefits (even those mentees who reported dissatisfaction), such as having an impartial person to discuss the injury with, talking to someone with similar experiences, individualised support, and social contact. These findings are consistent with other similar qualitative studies of peer mentoring, which found that mentors and mentees valued the impact of sharing and learning about experiences of brain injury (Northcott et al., 2022; Kolakowsky-Hayner et al., 2012; Hibbard et al., 2002; Hanks et al., 2012; Struchen et al., 2011; Coles and Snow, 2011; Fraas and Bellerose, 2010; Kessler et al., 2014; Kersten et al., 2018; Levy et al., 2021). Despite the negative accounts of three mentees, one mentee and her carer were effusive in their praise for the positive impact of mentoring on her life. There was a clear disparity between the views of mentors, who all thought mentoring had been beneficial to the mentees, even those who did not have many meetings, and the views of three of the mentees. This incongruity can be explained by a few considerations. Firstly, the pairs got on well in person, with the interactions almost universally reported to be positive. However, on private reflection, the mentees did not think they benefitted in the ways the wanted to. The fact that partners had different types of brain injuries was the major factor in the mentees' dissatisfaction and applied to all three dissatisfied mentees. They did not feel they could really apply the mentor's experience to their own situations. The lack of organisation among two of the pairs, and the impact of external factors, also significantly contributed to the negative experiences.

The interviews with healthcare providers offered important insights into the recruitment issues. It is clear that the healthcare providers involved in the interviews were advocates of peer mentoring, but were still unable to recruit many mentees. Despite their positive views of the mentoring concept, they reported several factors which could deter services from referring people, such as issues relating to clients' behaviour and their physical, cognitive, and emotional suitability.

Mixed Methods Approach and Data Synthesis

The mixed methods approach to this study follows the MRC Framework and provides a richly layered evaluation. The qualitative perspective informs the interpretation of the quantitative results and provides some explanations for the feasibility aspects and complementary information to the quantitative measures. The synthesis has been particularly useful for providing insights into the reasons for organisational difficulties between pairs, the reasons for partnerships ending early, and the difficulties with recruiting mentees.

There are several elements of the synthesis which require further examination in order to explain contradictory or unclear findings. For example, there is nothing in the qualitative data to explain the increases in depression, anxiety, and stress among two mentees, the deterioration in home integration among all the mentees, or the reductions in carer burden. The mixed methods approach would have benefitted from asking questions in the qualitative interviews which were related to the same concepts which were measured quantitatively. For example, it would have been useful to ask questions which specifically

addressed the impact of the intervention on mood, participation, and carer burden.

Implementation Issues

The challenges of implementation shed light on the requirements for other projects which might seek to build on the work presented here. Despite being a small project, it was very time and resource intensive, mainly because the intervention is predicated on pairs of brain injury survivors meeting independently and without supervision. This posed several major issues with applications for ethical approval, leading to significant delays and added administrative burden. The fact that the intervention is, in effect, delivered by brain injury survivors who are also research participants meant that the mentors had to be screened adequately for suitability and trained effectively. This entailed DBS checks and a carefully designed and implemented training programme.

Identifying suitable mentees is a major issue for future implementation, with only one of the six mentees having had an entirely positive and beneficial experience. Part of this problem was the recruitment sources used, which may not have had access to people who were at an appropriate stage of recovery to benefit from mentoring. Overcoming the concerns of recruiters and effectively engaging them in the project is another factor that is time and resource intensive. Furthermore, it is essential to engage effectively with the participants in order to facilitate their ongoing involvement. My own engagement with participants was considered to be extremely helpful, reassuring, and effective by several participants, but ineffective by others. This is despite my attempts to

engage even more extensively with the ones who ultimately ended up dissatisfied, for the very reason that their partnerships were stalling. The issues lie with both researchers and participants, and there is a need for effective communication and for recruiting mentees who are most likely to engage and benefit from the intervention.

The issue of embedding the intervention within rehabilitation services is of particular relevance. For peer mentoring to be implemented effectively, it has to be in the right place, time, and context. This intervention was part of a research project, so was not embedded. Therefore, despite their positive views of peer mentoring, recruiters did not view this intervention as integral to their clients' rehabilitation programme, but rather as a bolt on which resulted in extra work and inconvenience for them. The HCPs involved in the design stage of this project felt that mentoring should be embedded within healthcare services in order to provide the necessary support and safeguarding, but that it should also have some degree of separation from clinical rehabilitation. In the future, it may be practical to implement a mentoring service run by healthcare professionals and with links to local rehabilitation services for recruitment, but which is a separate service aimed at transitioning people away from clinical rehabilitation.

The BCW and ICF: Reflecting on the Use of the Frameworks

Utilising the BCW and the ICF to inform the qualitative topic guides and analysis has highlighted the personal and contextual factors which influenced the mechanisms and outcomes of the intervention. The analysis at the level of these frameworks shows that physical and cognitive impairments were key

factors, which impacted on the organisation of meetings and the activities that people wanted to participate in. Feeding into the BCW, these are elements of capability which impact on opportunity and motivation.

The frameworks show that, to overcome activity limitations and participation restrictions, it is important to account for environmental factors and personal factors. By considering the environmental and personal factors in a participant's life when beginning the intervention, we can enhance their capability, opportunity, and motivation, limit their restrictions, and maximise their engagement with the project. For example, we can provide strategies and support to organise meetings; arrange meetings in advance; offer support with travel; arrange interesting and enjoyable activities; and find out about external factors in participants' lives that might restrict them and work out ways to overcome them. The emphasis peer mentoring places on the motivation and engagement of its mentors and mentees makes the elements of these frameworks extremely relevant and important.

6 Chapter Six: Discussion

6.1 Chapter Summary

This chapter will summarise, synthesise, and discuss the results of the three studies: the systematic review, the PPIE and qualitative design and development work, and the peer mentoring intervention. I will begin by synthesising and discussing the findings of the systematic review and the PPIE and qualitative study. This will help to situate my own findings from engaging with service users and professionals in the context of previous ABI peer mentoring studies and provide a framework for a discussion of the design of my peer mentoring intervention and its rationale. I will then discuss in turn the results of the feasibility questions, quantitative outcomes, and qualitative interviews. This will lead to a discussion of the clinical and research implications of the study. The strengths and weaknesses of the study will be assessed, and I will suggest ways that the findings and my experiences of delivering the project can inform future research.

6.2 Summary of Study Aims and Objectives

The overall aim of this PhD was to test the feasibility of delivering a peer mentoring intervention for ABI survivors and measuring its effects. To do this, I followed the MRC framework for developing complex interventions by conducting three studies, each with specific objectives. The first two studies aimed to inform the design of the intervention. Firstly, I conducted a systematic review to identify the current evidence for ABI peer mentoring (presented in Chapter Two). I then conducted a study involving stakeholder engagement, qualitative interviews, and focus groups to explore the perspectives of ABI

survivors, carers, rehabilitation providers, researchers, and peer mentoring providers regarding the design, delivery, logistical issues, and key outcomes of peer mentoring (presented in Chapter Three). The findings from these two studies allowed me to develop a peer mentoring intervention, which was delivered in phase three of the project (presented in Chapters Four and Five). This was a before-and-after study aimed at investigating the feasibility of delivery and implementation. The objectives were to recruit mentors and mentees; train mentors; establish pairings; operationalise the intervention; measure changes in participation, psychological wellbeing, hope for the future, quality of life, and carer burden; explore the perspectives of participants and recruiters; and identify logistical challenges and solutions. I used the ICF and BCW as theoretical frameworks to aid the development of the intervention and the analysis of the results. I employed the TIDieR guidelines as a framework for intervention design and reporting and followed the COREQ guidelines for reporting qualitative research.

6.3 Synthesis and Discussion of Studies One and Two

This section synthesises and discusses the results of the systematic review (Chapter Two) and the design and development PPIE and qualitative work (Chapter Three).

An appropriate starting point for this PhD, and for designing the intervention, was to identify the desire and need for ABI peer mentoring. The studies in the systematic review (Chapter Two) were weak in this area, mainly failing to present a strong reason for the use of peer mentoring. An exception to this was one study which reported initial findings from patients of their strong need for a connection with others with similar experiences of TBI (Moreci, 1996), while

another study used group peer support for stroke survivors to identify the need for the understanding and normalisation of post-stroke experiences and lifestyles (Kessler et al., 2014). The PPIE and qualitative study (Chapter Three) showed that there is a strong perceived desire for peer mentoring among survivors, carers, and professionals. The ABI survivors almost all said that they would have benefitted from a peer mentor during their own recovery, while the professional participants in both the development phase and post-intervention interviews said that peer mentoring was a potentially powerful alternative to professional clinical rehabilitation. However, it is possible that the sampling was biased towards people with a positive view of peer mentoring and that these opinions are not representative of survivors or professionals in general. This is because I used convenience sampling to find the participants, which is a method prone to introducing bias (Smith and Noble, 2014). Many participants had a history of participating in research with the university, connections to peer mentoring services or research, or were motivated to volunteer because of an interest in the topic or prior experience. Furthermore, most ABI survivors in the development interviews and focus groups had sustained their injuries several years previously, so there was a lack of representation among recent survivors, who are the most likely target recipients of a mentoring intervention. Despite these caveats, there are still good reasons to believe that there is a strong desire for peer mentoring among the target demographic.

The findings highlighted that there is no one model and concept of peer mentoring, which corroborates recent reports into the broader field of peer support interventions (including peer mentoring), which found ‘tremendous heterogeneity’ in the way they are designed, implemented and evaluated, which

hinders building an evidence base and establishing best practice (Magasi and Papadimitriou, 2022). Key considerations when designing peer support interventions are the target populations, the point of intervention (e.g., at the inpatient, outpatient, or community stages), services, modes of delivery, dosages, outcomes, peer characteristics, peer training, supervision, and setting (Magasi and Papadimitriou, 2022). The different elements of the intervention models in the studies in the systematic review were interconnected and co-dependent on each other. For example, the studies involving mentees in the early stages of recovery tended to have an inpatient setting and involve peers visiting hospitals or rehabilitation units to provide emotional and informational support on a one-off basis (Moreci, 1996; Kessler et al., 2014), whereas the outpatient studies involved multiple meetings in community settings or by telephone (Hibbard et al., 2002; Struchen et al., 2011; Hanks et al., 2012; Kolakowsky-Hayner et al., 2012).

The theories underpinning interventions help to explain how and why they work the way they do, so theory is an important consideration when designing an intervention (Fleury et al., 2018). Therefore, it was important to identify the theoretical frameworks underpinning ABI peer mentoring interventions. However, peer support interventions have been described as “a method in search of a theory rather than the application of theory to practice” (Turner and Shepherd, 1999). The studies in the systematic review tend to conform to this characterisation, in that they are not underpinned by detailed, empirical, models intended to explain the behaviour change they aim to influence or the mechanisms by which they will be affected. Research into peer mentoring for SCI has been more explicitly theory-based, with models of change based on

self-efficacy theory (Houlihan et al., 2017; Gassaway et al., 2017), self-determination theory (Sweet et al., 2018), transformational leadership theory (Beauchamp et al., 2016), and transformative learning theory (Jones et al., 2019). The ABI peer mentoring studies published since the systematic review show a tendency for ABI peer mentoring research to be moving in a similar direction, with new focusses on transformational leadership (Masterson-Algar et al., 2020), and self-efficacy (Levy et al., 2021) as models of change. The interviews and focus groups indicated that the key mechanisms by which mentoring can help mentees are the sharing of experiences, empathy and understanding, encouragement, reassurance, and information, which are all connected to elements of transformational leadership, self-determination, and self-efficacy.

Participants in the PPIE workshops thought that peer mentoring should help to improve people's outlook to recovery; enhance self-confidence; reduce stress, anxiety and depression; facilitate increased social and leisure activities; enhance personal relationships; and enable mentees to make better judgements. It should have a broad impact across a variety of areas, but also a clear focus for each individual and be adaptable to personal preferences. Importantly, it should be convenient and enjoyable. The key outcomes identified in the interviews and focus groups were personal goals, improved mood, social and leisure participation, confidence and coping strategies. The identification of many of these outcomes as amenable to improvement by peer mentoring was broadly supported by the systematic review studies, which examined outcomes related to participation (Struchen et al., 2011{Hanks, 2012 #33; Hibbard et al., 2002; Fraas and Bellerose, 2010; Kolakowsky-Hayner et al., 2012), mood

(Struchen et al., 2011; Hanks et al., 2012), life satisfaction and quality of life (Fraas and Bellerose, 2010; Struchen et al., 2011; Hanks et al., 2012), disability management (Kolakowsky-Hayner et al., 2012), behaviour management (Hanks et al., 2012), and return to employment/education (Kolakowsky-Hayner et al., 2012). The most recent ABI mentoring studies also lend support to the importance of these outcome areas, with studies examining participation (Kersten et al., 2018; Masterson-Algar et al., 2020; Levy et al., 2021), mood (Levy et al., 2021; Hilari et al., 2021), and quality of life (Levy et al., 2021). Furthermore, a systematic review of SCI peer mentoring has identified 87 outcomes, grouped into six higher order themes and 18 sub-themes, which also endorse those identified in Chapter Three (Rocchi et al., 2021). The higher order themes were adaptation (including skill development); connection (with other people); growth (including improving outlook, hope for the future, adjustment, identity, and motivation); independence; knowledge (including condition-specific knowledge and resources); and participation (including health and recreational activities and community involvement).

Magasi and Papadimitriou have highlighted the importance in the development of peer support interventions of where in the continuum of care to implement them (Magasi and Papadimitriou, 2022). The authors argue that the intervention goals, theoretical framework, and the participants' acceptance of their condition and readiness for change should be considered when making this decision. The results of exploring this issue in the development study suggested the importance of early intervention in order to provide impetus to early recovery, help with transition back to the community, and give people early support and reassurance from someone who knows what they are going

through. However, the issues of the acceptance of condition and readiness for change are particularly pertinent after brain injury, with insight and self-awareness often severely impaired for a considerable time (Smeets et al., 2014; Robertson and Schmitter-Edgecombe, 2015; FitzGerald et al., 2012). Therefore, the appropriate timing may be best assessed on an individual basis. This is further evidenced by one of my TBI interview participants, who said they would not have been ready for mentoring for a year or more after their injury, when they finally understood what was wrong. A professional participant also argued that there could be a danger to introducing a mentor too early before the cognitive effects on normal life have become apparent. The studies in the systematic review either focussed on inpatients in the early stages of recovery (Moreci, 1996; Kessler et al., 2014), recently discharged from hospital (Hanks et al., 2012), or did not specify limits on timing, preferring to take a flexible approach (Struchen et al., 2011; Coles and Snow, 2011; Kolakowsky-Hayner et al., 2012). Some recent studies have been clearer on this issue, with mentees recruited as they were transitioning from hospital back to home (Kersten et al., 2018; Hilari et al., 2021; Northcott et al., 2022), or within six months of stroke (Masterson-Algar et al., 2020).

The key traits of mentors identified by the PPIE work were good self-awareness and insight, motivation, self-confidence, organisational skills, experience, people skills, independence, knowledge of brain injury and resources, and understanding of their responsibilities. The characteristics identified in interviews and focus groups were being a good listener, positive attitude, honesty, understanding and patience, willingness to learn, insight and self-awareness, and a nurturing tendency. The evidence supports these areas,

with studies in the review requiring mentors to be good listeners (Hibbard et al., 2002; Moreci, 1996; Fraas and Bellerose, 2010), empathetic (Coles and Snow, 2011; Moreci, 1996; Hibbard et al., 2002; Fraas and Bellerose, 2010), willing to share life experiences (Moreci, 1996; Coles and Snow, 2011), motivated to help others (Hibbard et al., 2002; Fraas and Bellerose, 2010; Hanks et al., 2012), and to have good personal adjustment, social competency, and lack of behavioural problems (Hibbard et al., 2002; Fraas and Bellerose, 2010; Struchen et al., 2011; Hanks et al., 2012; Kolakowsky-Hayner et al., 2012). The post-intervention interviews confirmed some of these key mentor traits, with good listening skills cited as especially important. The mentors identified the need to listen to their mentee's needs and see things from their perspective, particularly regarding the organisation of meetings and the barriers presented by the mentee's impairments. Openness, insight, and trustworthiness were also identified as essential qualities, as was the need to strike a balance between optimism and realism. A study of SCI peer mentors, using Delphi methodology, identified 225 key characteristics of mentors with six overarching themes which support those identified in this study: competencies (e.g., good listener); personality characteristics (e.g., caring); emotional state (e.g., calm); outlook (e.g., positive); reason for mentoring (e.g., desire to make a difference); and role modelling (e.g., having inspiring qualities) (Gainforth et al., 2019). These are qualities it is important to look for in potential mentors and to cultivate in mentor training, which I attempted to do in the mentor recruitment and training elements of this project.

In the qualitative interviews and focus groups, opinions on the best mode of delivery varied, with positive and negative aspects cited for the main options.

Face-to-face contact was considered to have the advantage of improved communication, facilitated by using cues from eye contact and body language, and of allowing participants to go out, engage in activities, and practice skills such as using public transport. However, participants also thought it could be inconvenient, lead to safety issues and place extra demands on participants, which could be avoided by utilising telephone and videocalls. Emails and text messages were considered useful to complement face-to-face or telephone meetings, but not as a primary mode of contact.

Evidence from the systematic review supports utilising the mode of delivery best suited to the aims of the intervention. For example, studies aimed at improving participation, social contacts, and community integration employed face-to-face meetings (Struchen et al., 2011; Hanks et al., 2012; Kolakowsky-Hayner et al., 2012). More recent studies with similar objectives also primarily utilised in-person contacts, intended to facilitate social interactions and activities (Kersten et al., 2018; Masterson-Algar et al., 2020). In the interviews and focus groups, venues for face-to-face meetings were considered to be a matter of personal preference, convenience, accessibility and the planned activities, which was an approach taken by previous studies, which allowed meetings in the community at venues of the participants' choosing (Struchen et al., 2011; Hanks et al., 2012; Kolakowsky-Hayner et al., 2012; Coles and Snow, 2011; Kersten et al., 2018; Masterson-Algar et al., 2020). Other studies have taken the approach of using the same venue for all face-to-face meetings, such as a community day centre (Fraas and Bellerose, 2010), or hospital meeting room (Ozier and Cashman, 2016), which provides structure and consistency, removing the need for planning and organisation, but also

restricting participants. Other studies have primarily employed telephone conversations, allowing frequent contacts with minimal inconvenience, including one study in the systematic review (Hibbard et al., 2002) and another recent study in Canada (Levy et al., 2021). These have primarily focussed on informational and emotional support, with conversations about brain injury-related problems, although information sharing has also been used to promote activities and participation (Hanks et al., 2012; Levy et al., 2021), an approach also advocated by participants in the development study in this project. Several studies have employed a flexible approach, allowing different modes of contact according to each participant's preference (Hanks et al., 2012; Struchen et al., 2011; Kolakowsky-Hayner et al., 2012), which allows for tailoring the preferred mode of contact to the mentee's goals. For example, if the pair just want to talk then telephone contact is acceptable, whereas if they want to get out for an activity then they would need to meet. As my intervention focussed on improving participation, face-to-face meetings were the main mode of contact.

The PPIE and qualitative work explored participants' views on the social and leisure activities that could be part of mentoring meetings. Previous ABI peer mentoring research identified in the systematic review has provided little information about this. In one study, it was reported that the pair played board games occasionally, while also participating in recreational activities together at the day centre where they had their meetings (Fraas and Bellerose, 2010). However, even other studies aimed at improving social and leisure participation, and which involved face-to-face meetings, did not report the pairs engaging in such activities during meetings (Struchen et al., 2011; Hanks

et al., 2012). In another recent intervention, aimed specifically at improving post-stroke social and leisure activities, the pairs did not engage in activities during meetings, but instead met to plan how the mentee could get involved in an activity of interest to them (Masterson-Algar et al., 2020). The lack of details available in this area is perhaps indicative of the logistical problems inherent in the organisation and planning of activities, which will be discussed in more detail later in this chapter. In the PPIE and qualitative work for this study, a wide range of possible activities of broad appeal were mentioned, such as going for walks, going to the cinema, going bowling, going to the theatre, etc. However, the best approach was said to be to target the interests of the mentees, their personal goals, and the capabilities of both partners.

Participants in the PPIE and qualitative design work were asked about the criteria by which mentoring pairs should be matched. Mutual interests and personal rapport were agreed to be important, as were common experiences of recovery after brain injury. Common interests were used to match people in several of the systematic review studies (Hibbard et al., 2002; Struchen et al., 2011; Kolakowsky-Hayner et al., 2012) and the recent ABI studies (Kersten et al., 2018; Hilari et al., 2021; Levy et al., 2021), highlighting the importance of this factor. There was less consensus among my qualitative participants regarding matching for type of injury, with some people saying it was important while others felt that it was not necessary. However, common experiences of issues surrounding brain injury was felt to be essential, even if the causes of the injuries were different. The previous studies have mainly concentrated on one type of injury, usually TBI or stroke, so there is no information regarding this criterion. They have employed a variety of other

matching criteria between them, with some studies using a lot (Hibbard et al., 2002; Coles and Snow, 2011) and others employing a more flexible approach (Kersten et al., 2018), or not reporting any criteria (Hanks et al., 2012), while the interventions involving hospital visits did not use matching criteria at all (Moreci, 1996; Kessler et al., 2014). Age (Hibbard et al., 2002; Kolakowsky-Hayner et al., 2012; Struchen et al., 2011) and gender (Fraas and Bellerose, 2010; Hibbard et al., 2002; Kolakowsky-Hayner et al., 2012; Struchen et al., 2011) (Kersten et al., 2018; Hilari et al., 2021) have been commonly used criteria in previous studies. However, there were different views among my qualitative participants about their importance, with some people saying they did not matter while others thought that matching for these factors could help with finding common interests and building rapport. Geographical location was not discussed in my engagement work but was an important matching factor in studies using face-to-face interventions, especially those recruiting from a large area (Coles and Snow, 2011; Hibbard et al., 2002; Struchen et al., 2011; Kolakowsky-Hayner et al., 2012; Masterson-Algar et al., 2020). Further evidence regarding this issue comes from a Delphi study of SCI peer mentoring matching factors, which identified the most important criteria (for community settings) as ‘mentor’s knowledge matches mentee’s needs’, ‘time availability’, ‘outlook and approach’, ‘knowledge about community-based resources’, ‘similar lifestyle goals that the mentee wants to achieve/experience’ and ‘experience with similar challenges that the mentee might encounter’ (Gainforth et al., 2019).

The ideal number, duration, and frequency of meetings depends on the needs of mentees, practicalities (such as convenience for participants) and the goals of

the intervention. However, there was a consensus that several meetings, on a regular but not excessive basis, would be needed for the intervention to be effective. They should be every one or two weeks, and approximately one hour, although the length would depend on activities. Previous studies have operated models along similar lines to this, excluding ones which delivered one-time-only visits in a hospital setting with telephone follow-ups as required (Moreci, 1996; Kessler et al., 2014). Several studies have set the number of meetings at six (Struchen et al., 2011; Kersten et al., 2018; Masterson-Algar et al., 2020; Hilari et al., 2021), one at eight (Coles and Snow, 2011), and another at ten (Fraas and Bellerose, 2010), with frequencies being weekly (Fraas and Bellerose, 2010; Coles and Snow, 2011) or fortnightly (Struchen et al., 2011; Kersten et al., 2018), while others left the number of meetings and their frequency at the discretion of participants (Hibbard et al., 2002; Hanks et al., 2012; Levy et al., 2021). Several studies have left the duration of meetings up to participants (Struchen et al., 2011; Hibbard et al., 2002; Hanks et al., 2012; Kolakowsky-Hayner et al., 2012; Kersten et al., 2018), while others have recommended pairs meet for one hour (Coles and Snow, 2011; Hilari et al., 2021). The important factor again here is that the delivery method suits the aims of the study. According to participants one hour is perfect for talking, but if they want to do an activity then the duration needs to be flexible.

The PPIE and qualitative development work showed that the participants placed high importance on providing thorough training for mentors. The PPIE identified mentor training as a way of reducing the risk factors presented by peer mentoring and the professional interviewees also strongly emphasised this. For example, professional interviewees said that mentors should be trained

on safeguarding issues, identifying risk factors in the mentee's life (e.g., self-harm) and on appropriate behaviour and boundaries. Training should also equip mentors with knowledge and information on a range of relevant topics which should guard against another risk identified in the interviews, that of mentors providing incorrect information. Training is also linked to the characteristics of a peer mentor discussed above, some of which mentors can be trained to develop, for example, active listening skills and focusing on the needs of the mentee. The importance of this topic is highlighted by the fact that all the studies in the systematic review, and the ABI peer mentoring studies published since the review, have devoted significant time to the planning and delivery of mentor training programmes, although the papers varied in the detail they provided. Training has tended to consist of several hours of face-to-face training over full-days or multiple sessions, some in groups (Hibbard et al., 2002; Struchen et al., 2011; Hanks et al., 2012; Kessler et al., 2014; Kersten et al., 2018; Masterson-Algar et al., 2020; Hilari et al., 2021; Levy et al., 2021; Moreci, 1996), while others were on a one-to-one basis (Coles and Snow, 2011; Ozier and Cashman, 2016). Several programmes have provided trainee mentors with written guides and manuals (Hibbard et al., 2002; Coles and Snow, 2011; Struchen et al., 2011; Hanks et al., 2012), with the Struchen manual still available online and which was an important resource for me in planning the training for this project. Recently, Kersten et al. also published detail of their training programme, which also proved to be a useful resource for my design (Kersten et al., 2018).

The topics addressed in the published ABI mentor training guides provide support for the importance of those suggested in the development study,

including communication and listening skills (Coles and Snow, 2011; Moreci, 1996; Hibbard et al., 2002; Kessler et al., 2014; Hanks et al., 2012); knowledge of brain injury and effects (Moreci, 1996; Fraas and Bellerose, 2010; Hibbard et al., 2002; Struchen et al., 2011; Hanks et al., 2012); techniques for building relationships and rapport (Fraas and Bellerose, 2010; Coles and Snow, 2011; Hanks et al., 2012); accessing community resources (Fraas and Bellerose, 2010; Struchen et al., 2011); enhancing mentees' social skills (Hibbard et al., 2002; Fraas and Bellerose, 2010; Struchen et al., 2011); and handling difficult situations/inappropriate behaviour (Fraas and Bellerose, 2010; Struchen et al., 2011). However, participants in the PPIE and qualitative work also emphasised that the training should not be overly demanding or intimidating for mentors, so should not expect them to learn highly technical or complex subjects. Kersten explains that they took care not to professionalise the role and turn the peers into "quasi-health professionals", so provided only limited information about clinical subjects and focussed on the mentors' personal experience (Kersten et al., 2018).

As well as those highlighted above, other risks, safety and logistical issues discussed by development study participants included a lack of clearly defined structure and boundaries; lack of support for mentors; impatience from mentors; a pushy attitude from mentors; awkward questions; sharing of alcohol or drugs; inappropriate/risky activities; inappropriate behaviour, such as sexual pressure of financial manipulation; going to each other's homes; mentees developing an unhealthy dependence on the mentor; providing negative or unrealistic expectations of recovery; pressure on mentors; and mentors doing the wrong thing. Some of these issues were cited by professional participants in

the qualitative interviews and PPIE work, and it is interesting to note that none of them were reported by studies in the systematic review. Rather, the issues reported in those studies related mostly to problems with research aspects such as recruitment, matching and adherence (which will be discussed later); scheduling times and locations for meetings (Kolakowsky-Hayner et al., 2012) (Kessler et al., 2014); budgeting for transport (Kolakowsky-Hayner et al., 2012); and project staffing resources (Struchen et al., 2011; Kessler et al., 2014). Therefore, there was a disparity between the potential problems that were anticipated and those that have previously been found in practice.

The use of the TIDieR framework when extracting data from the systematic review and designing the topic guides for the interviews and focus groups allowed me to gather evidence for the essential elements of a peer mentoring intervention. The use of the BCW in the analysis of the data allowed me to understand how the intervention could have a positive influence on the targeted aspects of a mentee's behaviour. For example, making the intervention safe and simple facilitates the opportunity to engage with peer mentoring. The use of the ICF as another framework to inform the analysis allowed me to see ways in which mentoring could limit the impact of impairments on engagement with activities and participation. For example, by provision of information, encouragement, and reassurance a mentor could help the mentee to learn, accept, and adapt to the effects of their injuries and reduce their detrimental impact. These frameworks have not been employed in the design or evaluation of a peer mentoring intervention before, so the approach is innovative, novel, and adds to the literature on the theoretical foundations for peer mentoring work.

6.4 Feasibility

6.4.1 Recruitment and Sample

Mentors

There were twenty applications from people interested in being mentors during the six-month recruitment process, which was more than the target of fifteen. This indicated the feasibility of the multi-pronged recruitment methods. Recruiting via adverts on brain injury charity websites was the most successful method, with nine responses, while six referrals came from rehabilitation teams conducting mentee recruitment who had former clients suitable to be mentors. Recruiting via charity day centres and former University research participants was also productive.

The subsequent attrition through to the completion of training resulted in nine trained mentors consenting to take part, below the target but comparing favourably with other recent studies (with far greater resources) in UK community settings, one of which had five mentors (Masterson-Algar et al., 2020), while another recruited twelve, of whom ten were trained and completed the intervention (Hilari et al., 2021). Similarly, a recent trial in Canada had six mentors (Levy et al., 2021). In fact, no other study of brain injury peer mentoring which has recruited mentors specifically for a research project has reported as many applicants or trainees as this one. Hanks' trial had far larger numbers of mentees but did not report details about mentor recruitment or numbers (Hanks et al., 2012), while some other studies have recruited from existing, long-term mentoring programmes (Hibbard et al., 2002; Kolakowsky-Hayner et al., 2012; Levy et al., 2021). Kersten et al. had funding for six mentors and six mentees, and they achieved that target,

although they reported sending letters to 34 potential mentors, with nine of those attending training and eight completing training (Kersten et al., 2018). My findings indicate that there is substantial interest among experienced brain injury survivors to use their experience to help others. The recruitment methods showed potential for identifying the people most likely to show interest, with the internet and social media being particularly promising recruitment sources for future studies.

Four potential mentors were ineligible due to living outside the catchment area, which would not have precluded them if remote contact methods were used for mentoring meetings, an option which should be considered for future projects. Three of the twelve who participated in the training withdrew after one session, with two stating that taking part in the training helped them to realise that they were not ready to be mentors. This was an interesting finding and may indicate that the training was successful in conveying the requirements and demands of the mentoring role. Regarding the demographic characteristics of the mentors, only one of the training participants was non-white and that person withdrew after one training day. This lack of non-white participants is reflected in the rest of this study and is a limitation which reduces the generalisability of the findings.

Mentees

The recruitment of mentees was one of the most challenging aspects of this study, but also one of the most potentially informative. There were very few referrals under the initial eligibility criteria of <six months post-discharge, so this was increased to <12 months and the recruitment period continued for nine

months. Overall, 21 people expressed an interest to the recruitment teams, and only four of these were ineligible, which suggests the feasibility of recruitment. However, eleven of those participants did not proceed beyond the initial expression of interest and were resistant or non-responsive to attempts to contact them or to further encouragement from the recruitment teams. Six people provided consent, but two withdrew due to the delay in matching them and beginning the intervention. The final total of four mentees was 27% of the target total and suggests the lack of feasibility of either the recruitment of mentees, the eligibility criteria, or other aspects of the methods used.

In previous studies, the recruitment of mentees was also widely reported to be challenging (Hanks et al., 2012; Hibbard et al., 2002; Kolakowsky-Hayner et al., 2012; Struchen et al., 2011). Even studies drawing on pre-existing mentoring services with large numbers of participants have failed to recruit in large numbers for research purposes (Levy et al., 2021; Hibbard et al., 2002). Some recent studies had small numbers of mentees, with six mentees in two studies (Levy et al., 2021; Kersten et al., 2018), and five in another (Masterson-Algar et al., 2020). However, the recent trial of peer befriending for stroke survivors identified 738 patients, of whom 75 were eligible, 62 consented, and 56 were randomised, although the researchers also stated that recruitment was challenging and took place over 18 months, which had to be extended from the planned twelve (Hilari et al., 2021).

There were reasons for recruitment difficulties in previous studies which are relevant to my own. Struchen et al. cited a primary reason for withdrawal before mentoring began as a decrease in interest due to the lengthy time between recruitment and matching (Struchen et al., 2011). In my study, the

protracted time taken to recruit mentors and mentees separately and then match them, meant that two people who consented to take part as mentees were waiting too long and withdrew. In the qualitative interviews, the mentees who took part in the study also referred to frustrations with the waiting time. To overcome this issue, it would be necessary to recruit substantial numbers of mentors and mentees concurrently, and reliable recruitment methods would be needed to guarantee this. Hibbard et al. reported a lack of interest among the mentees in their community programme for the extra commitment of taking part in the research procedures (Hibbard et al., 2002). This is a potential problem for all research projects, and it is important to maximise incentives and motivation for potential participants. Healthcare providers in the post-intervention interviews cited the unwillingness of many clients to get involved with services in addition to the rehabilitation they already have, especially when there is significant effort and commitment required. One recent project cited a lack of readiness among the people identified as potential mentees and identified their eligibility criterion of <six months after stroke as a potential reason for this (Masterson-Algar et al., 2020). The authors also stated that, conversely, others had already progressed beyond the need for mentoring. These observations are supported by my findings, with no referrals under the original <six months criterion and continuing difficulties when re-specified as <12 months. The qualitive development study interviews also showed that some people thought that the first few months after injury may be too soon for some people, who have yet to develop sufficient awareness of their difficulties and needs. Future studies could adopt a more flexible approach to mentee eligibility regarding the timing of the intervention.

The post-intervention interviews with recruiters showed that clinicians may be reticent to refer clients with impairments which they thought might make participation difficult for them (e.g., physical disabilities and cognitive impairments), prevent them from benefitting (e.g., lack of insight), or present problems for other people (e.g., disinhibited behaviour). In some cases, professionals may not refer clients even if they meet the eligibility criteria and would benefit from the intervention. This is because of judgements made by the clinicians regarding how much burden to place on the patient and because of concerns and uncertainty regarding an intervention which they do not control. Another reason was the lack of priority research recruitment has for clinicians who have other more pressing day-to-day concerns. To improve recruitment, there needs to be extensive engagement and training with professionals at recruitment sites. For this project, I visited all the sites at the outset of recruitment, gave presentations, and had discussions with the staff, who were all positive about the study and expressed willingness to refer. However, the feedback showed that this willingness may have given way to caution regarding some potential participants. A way to overcome this could be to conduct site initiation visits in which staff are actively involved in planning the eligibility and recruitment aspects of the project. Hilari et al. reported that they provided training to staff at recruitment sites on their study criteria and consenting processes for people with aphasia (Hilari et al., 2021). A similar approach could be taken with training for brain injury-related recruitment processes.

Ongoing engagement with recruiters is also essential and I maintained regular contact with the recruitment sites throughout the process, as Hilari et al.

reported doing on a monthly basis to monitor targets (Hilari et al., 2021). A project with sufficient funding and staffing could employ an onsite recruitment officer embedded within the site team. This person could also have access to caseload details, continually review clients for eligibility, and attempt to recruit anyone who meets the criteria. This would remove any issues of subjective judgement from clinicians regarding the clients' suitability or ability to engage with the project.

Difficulties with recruitment were also said to arise through the lack of availability of eligible clients, with some services receiving brain injured patients many months after their injury, keeping them on the books for a lengthy period and receiving few new patients. Other services have very severely injured patients who would not meet the eligibility criteria, while others have patients only for a very short time. There were also several recruitment sites which did not refer any clients and told me that they simply had not identified anybody eligible.

Despite small numbers of participants, other feasibility studies have concluded that peer mentoring is feasible to operate (Kersten et al., 2018; Levy et al., 2021). My conclusion is that a large-scale trial using similar methods employed in this study would not be feasible. However, further small studies are feasible and, with the suggested adaptations to the recruitment methods, greater numbers of mentees should be attainable.

Demographic Characteristics

The mentees' demographic characteristics were different in important ways to the mentors. The mean age of mentees was 64.25 (51–79), compared to 40.75

(30–49) for mentors, while only one of the mentees had a TBI (two with strokes and one with encephalitis), compared to three mentors with TBI and one with anoxic injury. These differences in the groups, combined with the large travelling distances between them, meant that it was difficult to make acceptable matches between pairs.

Carers and Healthcare Providers

Three of the four mentees nominated carers to participate. The other mentee did not have anyone she considered to be a carer and who she felt it appropriate to nominate. It is reasonable to conclude that it would be feasible in a larger study to recruit a high proportion of the mentees' carers. However, none of the mentees nominated a healthcare provider involved in their ongoing rehabilitation treatment, as was the original intention. This is because the mentees were either discharged from the services soon after referral or did not have a regular clinician they wanted to nominate. It is likely that these issues would also occur in future projects. Despite this, it was straightforward to obtain the consent of healthcare providers from five of the participant identification sites to participate in qualitative interviews, which provided important insights into the recruitment issues. There have been no other studies that have conducted similar qualitative or quantitative assessments with carers or healthcare providers of mentees, or recruiters, so this aspect of the project has provided valuable new perspectives.

6.4.2 Data Collection Procedures

All participants completed the quantitative measures quickly and there were no missing data. This included the participant with severe aphasia, who was able

to complete them by indicating the correct multiple-choice options. The qualitative interviews were also completed without difficulties. Travelling to each participant's home using public transport to conduct the baseline assessments was time consuming and costly, but was easily accomplished given sufficient time between each visit. The post-intervention quantitative and qualitative assessments were conducted by telephone, which was convenient for participants and interviewers. The data collection procedures were deemed to be feasible based on these results. However, completing the measures in-person with each participant, or scheduling considerable numbers of telephone assessments, may not be feasible for a larger study. This project did not evaluate the feasibility of postal, email, or online measures, which may need to be considered if there are many participants over a broad geographical region.

6.4.3 Acceptability and Suitability of Procedures

Mentor Training

Potential mentors were asked to travel to the University of Nottingham for two training days, held on consecutive weeks. It has been common for previous studies to conduct mentor training in a similar way; in-person, in groups, at a single location, such as a hospital or university (Moreci, 1996; Hibbard et al., 2002; Struchen et al., 2011; Hanks et al., 2012; Kessler et al., 2014; Kersten et al., 2018; Masterson-Algar et al., 2020; Hilari et al., 2021; Levy et al., 2021), which offers the advantage of training all the mentors together at one time. It also allows the trainers to conduct discussions and exercises and assess the participants' suitability for the role. However, it does cause the inconvenience of travel, expense, and time commitments, and this project also required participants to complete applications for Disclosure and Barring Service

Checks and university volunteer forms, which needed to be finalised in-person at the university. The participants' expenses were covered, but this required them to keep receipts and submit expenses forms. Therefore, there were significant demands placed on participants, who all had brain injuries and some level of physical and cognitive impairments. This issue is an important consideration when developing mentor training programmes, but the acceptability of their training was not addressed in detail by previous studies.

There were twelve mentor applicants at the two training days. Participants did not report problems with travel or parking, showing that the accessibility of the venue and the travel instructions were acceptable. Participants were given support to fill in all necessary forms and complete the DBS and volunteering processes. Two participants withdrew from the process after attending, stating that he did not feel ready to be a mentor, while another did not respond to further contact. The total of nine people from a total of twelve who successfully completed the training represents 75% retention over the process and indicates feasibility and acceptability, comparing favourably to other projects which have run similarly structured training programmes (Hilari et al., 2021; Levy et al., 2021; Masterson-Algar et al., 2020; Kersten et al., 2018).

The content of the training was influenced by previous studies and by the development work, as discussed previously. The presentations, exercises, and discussions covered the structure of the project, the role of a mentor, sharing experiences, mentor characteristics, becoming a mentor, the effects of brain injury, participation in activities, mentoring goals and motivation, and the challenges of a peer mentoring relationship. Resources of particular importance in the development of the training were Hibbard et al.'s *Mentoring Partnership*

Program: Mentor Training Workbook (obtained directly from the author and no longer available online; published in 2005), Struchen et al.'s *Making Connections after Brain Injury: A Guide for Social Peer Mentors* (available at https://www.brainline.org/article/making-connections-after-tbi-guide-social-peer-mentors), and the detailed information on Kersten's training programme presented in their paper (Kersten et al., 2018). These resources presented useful information on challenges after brain injury, tools, strategies, and skills for mentoring, and communication, while there were excellent ideas for exercises on sharing experiences, practising listening skills, and developing ideas for activities (Kersten et al., 2018). I did not incorporate role-playing exercises because of information provided by Masterson-Algar that these activities made participants uncomfortable and they did not enjoy them (Masterson-Algar et al., 2020).

All five participants who returned their evaluation forms said that the sessions were well-structured, prepared them well to be mentors, and covered the topics well, while four agreed that the training covered everything needed to be a mentor. They enjoyed the exercises which involved thinking about topics from the perspectives of both a mentor and a mentee and appreciated the emphasis on patience and understanding towards the mentee. Thinking about goals and individual objectives also helped people to think about structuring mentoring sessions. Mentors in post-intervention interviews also reported that they enjoyed meeting and talking to the other mentors.

Some mentors said after the intervention that they would have liked some additional refresher sessions, which some projects with longer intervention periods have employed successfully (Moreci, 1996; Kolakowsky-Hayner et al.,

2012; Struchen et al., 2011). They also said they may have benefitted from further information from experts regarding specific types of brain injury and dealing with complex issues, which has been provided by studies with access to professionals such as speech and language therapists (Coles and Snow, 2011; Hilari et al., 2021) and psychologists (Kolakowsky-Hayner et al., 2012; Struchen et al., 2011; Kersten et al., 2018; Levy et al., 2021). The resource restrictions of the PhD project meant that it was not possible to provide further sessions or to have professionals available for training or ongoing advice, but future projects should consider these options if resources allow.

Intervention

I began each partnership with an introductory meeting, which I attended with each pair at a public venue, usually a coffee shop conveniently accessible to both partners. This was an innovative approach differing from previous mentoring programmes, which have tended to ask mentors to initiate the first contact, usually by telephone, to introduce themselves and arrange further meetings. The innovation was influenced by the findings of Masterson-Algar et al., who found that their participants were uncomfortable with initiating the first contact and that they would have liked the researcher to have taken responsibility for this and made the introductions (Masterson-Algar et al., 2020). My post-intervention qualitative interviews showed that the participants welcomed this approach and that the introductory meetings were successful.

After the introductory session, the pairs were asked to meet independently six more times, also at community venues rather than their homes. Of the four pairs, two met six more times, one met two more times, and one pair met once more. There were extenuating circumstances for the two mentees who ended

the intervention early, with one falling ill and spending time in hospital after two mentoring meetings, while another returned to work and no longer had as much time available. Therefore, it could be argued that 50% adherence from a small sample shows that the six-meeting schedule was acceptable and feasible. However, other studies have found wide variation in adherence to the intended numbers of meetings. Studies of single pairs have reported excellent adherence to regular one-hour meetings at a fixed location each time (Fraas and Bellerose, 2010; Coles and Snow, 2011). However, studies of multiple pairs which required the participants to arrange meetings at locations of their choice found that most pairs did not meet in-person the required number of times (Struchen et al., 2011; Hanks et al., 2012; Kolakowsky-Hayner et al., 2012). A one-to-one mentoring study involving non-brain injured mentors of brain injured mentees also reported that most pairs met infrequently (Johnson and Davis, 1998). A similar model of TBI peer mentoring in New Zealand reported four pairs meeting six times and two pairs meeting only once (Kersten et al., 2018) and, of Masterson-Algar's five pairs of stroke survivors, only one met six times, two twice, and two did not meet at all (Masterson-Algar et al., 2020). Adherence in the recent trial of stroke/aphasia peer befriending found that, of 28 participants in the trial arm, 21 (81%) attended all six meetings and 24 (92%) attended at least two. That study differed from the others in that befrienders visited partner's homes, so the mentees did not need to travel or to organise venues. The recent Canadian study also found wide variation in adherence among participants who needed to travel to meetings (Levy et al., 2021). Therefore, we can conclude that there is likely to be low adherence to a schedule involving several meetings which require organisation and travel.

Interestingly, the Peer Mentoring Questionnaire item asking about the number of meetings showed that the two mentees and two mentors who had the full quota of meetings all selected ‘Just right’, whereas those who had fewer selected ‘Not often enough’. This suggests that six meetings are acceptable, whereas previous studies have shown that ensuring adherence to that amount is challenging.

The answers to the Peer Mentoring Questionnaire showed that all the mentees and three of the mentors thought that the length of the sessions was just right. One mentor chose ‘Too short’ and explained in her post-intervention interview that this was because it would be difficult to travel a substantial distance, engage in an activity, and have a conversation about brain injury related issues, all in one hour. She clarified that, for the purposes of just meeting for a chat, one hour was appropriate. This question was an addition to the original Peer Mentoring Questionnaire, so there are no data from other studies on satisfaction with the duration of meetings. Studies which have left the duration (and mode) of meetings to participants have found wide variation, with Hanks finding that 36% of contacts lasted 5–15 minutes, 30% lasted 16–30 minutes, 19% were 31–60 minutes and 15% were longer than one hour (Hanks et al., 2012). The short meetings were predominantly telephone calls and, overall, the results show that one hour for face-to-face meetings is acceptable.

The qualitative interviews provided contrasting views about the acceptability of the intervention. One of the pairs who met seven times included a 79-year-old female mentee with severe aphasia after stroke and a 49-year-old female mentor with a TBI. Both partners and the mentee’s carer effusively praised the positive impact of mentoring. However, both mentees who withdrew from the

study said in interviews that they gained little benefit from mentoring, did not feel their mentor was an appropriate match, and found the communication with their mentor and the researcher to be inadequate. The other mentee who had seven meetings also appraised the intervention in negative terms, citing a lack of common experience with the mentor, which meant she derived little benefit from the meetings, and the delay between enrolment and matching, which meant that by the time the intervention started she no longer felt she needed it. However, the PMQs provided a slightly different impression, with three mentees selecting 'Very' satisfied with mentor (one 'Don't know') and three choosing 'Very' comfortable with partner (one 'Somewhat').

The reasons for these contradictory findings are difficult to explain adequately, but may relate to issues with the matching of participants. This is the first study of its kind to examine peer mentoring for people with all forms of ABI, as other studies have usually focussed on mentors and mentees with either TBI (Struchen et al., 2011; Hanks et al., 2012; Hibbard et al., 2002; Kersten et al., 2018; Levy et al., 2021), or stroke (Coles and Snow, 2011; Kessler et al., 2014; Hilari et al., 2021; Northcott et al., 2022). For this study, although I intended to match for injury type, that was not possible due to the differences between the mentor and mentee groups. Therefore, the pairs all had different injury types and qualitative interviews with the mentees showed that this was a significant reason for their dissatisfaction. The mentees reported that, although they got on well with the mentor, they felt that they did not have the shared experience and understanding of their circumstances that they expected from a peer mentor.

The issue of organisation for meetings and activities was another theme in qualitative interviews which may partly explain why one partnership went so

well, while the others did not. The mentees highlighted issues with physical and sensory impairments limiting choices of venue, while also causing difficulties with travel. One pair had problems contacting each other to make arrangements, which led to some misunderstandings and cancelled meetings. External circumstances also meant that participants could not find mutually convenient times to meet, and ultimately led to two mentees withdrawing from the study. Similar issues have been highlighted in other projects requiring participants to organise meetings and travel (Struchen et al., 2011; Kolakowsky-Hayner et al., 2012; Masterson-Algar et al., 2020). However, the pair who both enjoyed and benefitted from the project organised their meetings very effectively. The mentor drove, so she picked the mentee up at the same time and same day every two weeks and went to the same place. The mentor also communicated with the mentee's carer so he knew the arrangements and could remind the mentee. This removed any inconvenience and difficulty for the mentee and facilitated the meetings effectively.

6.4.4 Resources and Management Capacity

We have seen that peer mentoring has multiple, complex elements, including safeguarding and ethical issues, which are time and resource intensive. This study was challenging to manage as a lone researcher and a larger study would require increased staffing and management resources. Ongoing support throughout the course of the intervention was important to mentors and they appreciated the help I gave them through regular contact and discussions. Some mentors also expressed a desire for support from other mentors, which would enable them to share their experiences and feel connected to others in the same role. This would undoubtedly be beneficial to mentors but would also require

further management resources from project staff, such as in one recent project, which provided group supervisions/debriefs for mentors to allow them to meet and discuss issues (Kersten et al., 2018).

The level of resources and management required to run a peer mentoring intervention, along with the risk, ethics, and safeguarding issues, support the views of participants in the development work and the healthcare providers in the post-intervention interviews that peer mentoring should be linked to professional rehabilitation services. Other studies in both brain injury and spinal injury peer mentoring have predominantly been managed by teams of clinical professionals with the expertise and resources to provide the necessary practical and emotional support, supervisions, debriefs, monitoring, and safeguarding (Levy et al., 2021; Hilari et al., 2021; Kersten et al., 2018; Jones et al., 2019; Hill et al., 2019; Sweet et al., 2018).

6.5 Quantitative Outcomes

As this was a feasibility study with such a small sample size, the University Statistician advised me not to report statistical significance. Therefore, the results refer to the change from baseline to post-intervention assessments and must be interpreted with caution regarding the effectiveness of the intervention.

6.5.1 Participation

Participation was the main quantitative outcome of the study, and this was assessed using the Community Integration Questionnaire (CIQ) (Willer et al., 1993), the individual intervention goals, and the Peer Mentoring Questionnaire. As expected, mentors were almost unchanged on all the CIQ scales, but mentees, who it was hypothesised would show some improvements, in fact

worsened appreciably (-2.50) on the Home Integration scale group mean. However, the confidence interval did not exclude a difference of zero (-4.12–0.88) and there were improvements for all four mentees on the Social Integration and Productivity Scales. The analysis at the individual level showed that all mentees deteriorated on the Home Integration scale, while two improved on the Social Integration and Productivity scales. The analysis of the mentees' participation-related individual goals showed that the mentees achieved 'Have a reason to get out more', 'Go for walks', and 'Meet people', but did not achieve 'Go shopping', or 'Increase social activities'. The Social Support section of the Peer Mentoring Questionnaire showed that one mentee found the intervention a 'Great deal of help' with 'Support from Family', while one found a 'Great deal of help' and one 'Some help' with 'Support from Friends'. All four mentees found 'No help' for 'Support from the Community', 'Learning more about Friends and Social Issues', or 'Getting a New Support Group'. Mentors achieved all their goals, including the participation-related goals of 'Meet new people', 'Do something useful', 'Get out and do something different', and 'Meet other people with brain injuries'.

While we cannot derive any firm conclusions about the impact of this mentoring intervention on participation, the findings are informative. Firstly, there were appreciable changes for the mentees, compared to the lack of changes for the mentors, who could be expected to remain stable having made good recoveries. This suggests that the CIQ was sensitive to change for the participant group. This is a positive indication that it was an appropriate measure to use, which could be expected from its proven validity and reliability with TBI populations, although there is less evidence with other

forms of ABI (Willer et al., 1993; Zhang et al., 2002). The studies in the systematic review did not use the CIQ, but the recent study of stroke/aphasia peer befriending in London did use it and the intervention group mean deteriorated slightly at each assessment point compared to the usual care group, which improved slightly (Hilari et al., 2021). That study used an adapted version of the CIQ and did not report each scale separately, so we cannot compare the scales. Another recent study in Canada also used the CIQ and reported an overall deterioration for the intervention group, with a decrease on the Home Intervention scale from 4.6 at baseline to 3.6 after four months (Levy et al., 2021).

Levy et al. suggest that community integration may not be a feasible outcome to measure or try to improve in a short-term study, and instead may be a long-term outcome which can improve over time when other outcomes such as knowledge and skills have been improved first (Levy et al., 2021). The small improvements on the Social Integration and Productivity sub-scales suggest some positive impact on the participation concepts of the CIQ; however, the deteriorations on the Home Integration scale for my mentees require an explanation. The findings show that the mentees were receiving more help from someone else with home tasks at the time of the post-intervention assessments, such as with cooking and cleaning. This may indicate reduced independence, or it may instead indicate that they were busier with other activities outside the home, meaning that their partners were required to help more around the house. This interpretation is partially supported by the fact that all four mentees improved on either one or both of the Social Integration and Productivity scales. Along with the achievements of mentees in some

participation-related goals, and the positive reports of improved support from family and friends, these findings indicate some success for the intervention with improving participation. Another interpretation of the deteriorations on the Home Integration sub-scale is that mentees had become more aware of their difficulties and of the tasks they required help with and were asking people for help more. Friends and relatives may also have become more aware of the help that the mentees needed and were helping more than previously. It is not possible to say here whether the intervention had an influence on these changes. The results could have been due to normal changes in lifestyle or simply the result of natural progression and adaptation to the mentees' injuries. For example, one mentee had returned to work, which would have meant having less time for tasks at home and could explain their changes in the outcome measures.

Previous studies of ABI peer mentoring have had limited success with participation using different outcome measures. One U.S. study using the Peer Mentoring Questionnaire found that 9 out of 11 mentees reported no impact on social support from family, friends, and the community, with two reporting some impact or major impact on support from family and friends (Hibbard et al., 2002), while a much larger study (an RCT) found that 75% of the mentees reported help with support from family, 60% reported help with support from friends, and 42% reported help with support from the community (Hanks et al., 2012). Two studies have used the Mayo-Portland Adaptability Inventory (MPAI)–4 (Malec, 2011) and shown statistically significant improvements on the participation domain (Fraas and Bellerose, 2010; Kolakowsky-Hayner et al., 2012). The Craig Handicap Assessment and Reporting Technique–Short

Form (Whiteneck, 2011) has shown non-significant improvements on the Occupation and Social Integration sub-scales (Struchen et al., 2011; Kolakowsky-Hayner et al., 2012), while there have been non-significant improvements in perceived social support on the Interpersonal Support Evaluation List (Payne et al., 2012) among mentored participants (Struchen et al., 2011). A small study of mentoring using non-brain injured mentors, which was aimed specifically at increasing social contacts, found increased social activity levels (Johnson and Davis, 1998), whereas another more robust trial with brain injured peer mentors found no increases in social activity levels (Struchen et al., 2011). The findings of the current study regarding peer mentoring and participation, when considered in the light of these previous studies, provide some support for the idea that mentoring may be effective in helping people with participation, but that we still have not found the right approach or the right way to measure the outcomes.

6.5.2 Mood

The baseline mean scores for both mentees and mentors were all in the normal range on the depression, anxiety, and stress scales of the DASS–21, indicating that there were no clinical problems within the sample. There was a notable change from baseline to post-intervention for mentees on the anxiety scale (+5.5; CI -6.51–17.51), moving into the mild range (8.5), and also small increases for mentees on the depression and stress scales. The analysis at the individual level showed that there were notable deteriorations on all three scales for mentees two and five, who both moved into the severe range for anxiety and stress. The responsibilities and pressures of taking part in the intervention and being expected to arrange and attend meetings may have had

an influence on the changes in outcome scores. Another possible explanation for this is a change in life circumstances, unrelated to the project. For example, the mentee with the largest changes returned to employment during the project, so this could have been responsible for increased stress and anxiety. It should also be noted that the two participants in question reported some dissatisfaction with their involvement in the project, including frustration with the perceived lack of impact, so it is possible that their involvement caused them some stress and anxiety. However, the DASS-21 asks about the previous week and the measures were administered several weeks after the intervention concluded. Therefore, the changes could have been attributable to issues in the mentees lives over the previous week.

One previous study reported an increase in depressive symptoms among mentees after peer mentoring, suggesting a possible negative influence of the increased focus on the injury and awareness of the effects (Struchen et al., 2011). However, these findings have not been replicated prior to the current project. Struchen found no significant main or interaction effects on the UCLA Loneliness scale (Russell, 1996), while mentored TBI participants have shown lower scores compared to controls on global severity, somatisation, depression, and anxiety, although the only significant difference was on somatisation (Hanks et al., 2012). Recent studies have also found no significant changes or differences between intervention participants and controls on measures of depression (Levy et al., 2021; Hilari et al., 2021).

No previous studies have employed the DASS–21 and none have reported changes in anxiety or stress. However, my findings are worth noting and provide another reason for regular supervisions and discussions with both

mentors and mentees. It is also a reason for further assessment periods during the intervention and a larger study could also consider allocating resources for access to a clinical psychologist. It is an encouraging sign that mentors did not show any deteriorations, indicating that there were no negative impacts of talking about traumatic experiences, and the lack of negative impacts on mentors' mood has also been reported in a recent concussion mentoring study (O'Brien et al., 2023).

The responses to the mood section of the Peer Mentoring Questionnaire provide a different perspective and indicate some positive impacts of the intervention. One mentee said that mentoring was a 'Great deal of help' for 'Amount of happiness' and two said it was 'Some help'. One said it was a 'Great deal of help' for 'Amount of sadness/depression' and another 'Some help', while two said it was 'Some help' for 'Amount of anxiety'. These results suggest that the PMQs may reveal benefits of mentoring that the standardised measures were not sensitive to. Previous studies to have used the PMQs have also found impacts on mood-related items (Hibbard et al., 2002), with Hanks et al. finding that 70% of mentees were helped with their amount of happiness, and over 60% were helped with depression, anger, and anxiety (Hanks et al., 2012), despite finding no significant changes in depression or anxiety on the Brief Symptom Inventory (BSI–18) (Recklitis et al., 2017). There findings suggest that mentoring can have a positive impact on mood which has not been detected by standardised measures. This suggests that either the wrong measures have been used or that the subjective benefits have been short-lived.

6.5.3 Quality of Life

The Peer Mentoring Questionnaire also showed that there were perceived benefits of the intervention on empowerment and quality of life, with two mentees reporting that it was helpful with each of 'Ability to deal with life', 'Control over life', and 'Overall quality of life'. The lack of any notable changes on the EQ-5D-5L may indicate that it was a poor choice of assessment tool, which did not measure concepts amenable to change in this study. It mainly examines physical QOL, which was not likely to be influenced by the intervention. A different QOL measure might be more appropriate, and the following studies have employed several different options.

Quantitative results from one study in the systematic review provided support for improving quality of life (Fraas and Bellerose, 2010), with the mentee showing improvements in all domains of QOL on the Youth Quality of Life–Revised (YQOL–R) (Patrick et al., 2002), most notably in sense of self and general QOL, while the mentor showed improvements in self-esteem and self-actualisation on the Wisconsin Quality-of-Life Index (WQLI) (Diamond and Becker, 1999). These are elements of QOL which mentoring (both for a mentor and mentee) seeks to enhance, whereas physical health related areas are not so amendable to change. This idea is supported by a recent study, where there were no statistically significant changes on the Medical Outcomes Study Short Form-20 (Carver et al., 1999) between baseline, two months, and four months for mentees (Levy et al., 2021). However, Hanks et al.'s mentored participants showed significantly better health-related quality of life than controls on the Medical Outcomes Study 12-Item Short-Form Health Survey (SF-12) (Ware et al., 1996). Finally, the Satisfaction with Life Scale (SWLS) (Diener et al.,

1985) has indicated no improvements in the studies that have used it (Struchen et al., 2011; Kolakowsky-Hayner et al., 2012). There are no clear conclusions from these results. However, there are indications that mentoring has had an impact on subjective, psychological aspects of quality of life, but not on physical health-related elements.

6.5.4 Hope for the Future

The qualitative development work for this study suggested that hope for the future is an important outcome of mentoring, and previous studies have found this in qualitative interviews (Levy et al., 2021; Kersten et al., 2018). This was the first peer mentoring study to try to assess hope for the future quantitatively. However, the baseline scores on the Herth Hope Index were high for all the participants, which suggests a ceiling effect, with little margin for improvement. Furthermore, some items on the scale may not have reflected brain injury recovery; for example, 'I have a faith that gives me comfort', is open to interpretation as to whether it refers to religious faith and seemed confusing to some of my participants. The items also do not relate specifically to recovery from injury. A different measure of hope/optimism might also provide a better indication of this outcome. However, there are few, if any, standardised alternatives and this may be an area for development in future research.

6.5.5 Caregiver Burden

The CBS results indicated a reduction in carer burden, which is an interesting discovery, as carer burden has never been examined in previous ABI peer mentoring research. This is worth further, more rigorous investigation.

Although the intervention was short-term and infrequent, it is possible that it was enough to provide some respite from caring duties and reduce the impact on the carers. However, it is also possible that the burden would have reduced over time regardless of the intervention, as mentees have adapted to their injuries and become more independent. Furthermore, the perceived burden of caring can naturally fluctuate along with other factors in the lives of the mentees and carers. Other people may have started providing more support as time has passed, and pressures may have eased in other areas of the carers' lives, meaning that caring for the mentees is less stressful.

The results for Carer One in particular suggest that the CBS may have detected a genuine effect of the intervention. His mother had long-term care needs and a great reliance on him, which did not reduce over time. Therefore, any change in the burden he felt must have been attributable to something other than changes in his level of responsibility. His positive impression of the impact of mentoring on his mother reflected a positive impact on himself, which may have been detected by the CBS.

6.6 Qualitative Outcomes

The qualitative interviews revealed benefits of mentoring which were not apparent from the quantitative analysis, which has also been apparent from previous peer mentoring research. The mentees highlighted several outcomes and effective mechanisms of the intervention, although the one mentee who had a completely satisfactory experience participated only briefly in the interview because of her aphasia. One benefit of peer mentoring was said to be the mentor's impartiality, which allows people to be honest about their feelings

without worrying about upsetting friends or family members, and to be more relaxed and open than with a professional.

The shared experience of the mentor was said to be an important mechanism of mentoring, although the mentees said they would have preferred their mentor to have the same type of injury. Despite that, they still described the value of feeling understood by a mentor. Other qualitative studies have also found that sharing stories and experiences is a key device (Hibbard et al., 2002; Kersten et al., 2018), with the mentors' personal experiences of injury and recovery making them trusted and credible sources of support different from clinicians, family, or friends (Kersten et al., 2018).

The powerful impact of becoming a mentor was a major finding, as further evidenced in numerous other studies (Levy et al., 2021; Kersten, 2015; Hilari et al., 2021; Masterson-Algar et al., 2020). Mentors in the post-intervention interviews reported enjoying being useful and helping someone. Mentoring gave them a sense of purpose, boosted their self-esteem, gave their injury meaning, gave them perspective on their own recovery, and improved their interpersonal skills. Similarly, other qualitative studies have found that being a mentor was seen as a rewarding experience which enhanced personal confidence and provided a sense of satisfaction and achievement, with mentors appreciating the opportunity to help someone and give something back (Levy et al., 2021; Kersten et al., 2018; Masterson-Algar et al., 2020). Mentoring has increased social connections and provided personal growth and the feeling of making a positive difference to someone else's life (Kersten et al., 2018). The beneficial outcomes reported by mentors should be assessed and measured quantitively in future studies, such as with standardised measures of self-

esteem and confidence. Mentors also benefitted from sharing their experiences with other mentors on their training days (Kersten et al., 2018), which mentors in this study also enjoyed and would have liked to do more of at group supervision and debrief sessions such as other studies have used (Kersten, 2015; Moreci, 1996).

Being a peer mentor is a significant responsibility and the mentor interviews touched on some elements of early apprehension about whether they would be a good match for the mentee and whether they could have a negative influence. Mentors in other studies have also experienced worry and felt responsibility and pressure for their mentees' wellbeing, which has made them nervous and anxious (Kersten et al., 2018; Kessler et al., 2014). Negative impacts have also been reported in previous studies as a result of difficult conversations, problems with unsuitable partners, and organisational difficulties (Levy et al., 2021).

Both mentors and mentees described the benefits of the social contact provided by the meetings, which is beneficial for its own sake, regardless of long-term outcomes such as enhanced participation. These long-term outcomes may be much harder to measure than simple, short-term ones (such as enjoying spending an hour chatting), as Levy et al. have recently postulated (Levy et al., 2021). Instead, the long-term outcomes are a consequence of the key aspects of mentoring, which qualitative research has shown to be emotional, affirmational, and informational support (Levy et al., 2019). Kessler credited these forms of support with her participants' descriptions of the encouragement, motivation, validation, and decreased feelings of being alone which mentoring provided (Kessler et al., 2014).

Qualitative interviews can reveal a range of outcomes which may not even have been considered when designing an intervention. For example, participants in the recent RCT reported gaining knowledge and skills which enhanced their community integration, symptom management, organisational abilities, goal achievement, social support, perceived competence, self-efficacy, and empowerment (Levy et al., 2021). Each person derives something different from mentoring and it is extremely informative to explore these personal outcomes in qualitative interviews.

It would have been beneficial to have asked questions in the qualitative interviews which specifically related to participation, community integration, depression, anxiety, stress, hope for the future, and quality of life. This would have gleaned qualitative information on the same outcomes as those measured quantitatively. This also applies to the topics of feasibility issues, like burden of data collection, which could have been addressed in the topic guides.

6.7 Clinical Implications of the Study

This study can only have clinical implications if there is a willingness to implement peer mentoring within clinical services. The nature of the UK rehabilitation system means that if peer mentoring is viewed as a long-term support service, then this is unlikely to happen, as community rehabilitation provision tends to be time limited and focussed on primary needs, such as independent living (Barnes et al., 2018; Menon and Bryant, 2019). The clinicians interviewed for this project recognised that peer mentoring can help patients in ways that are different to clinical rehabilitation, but cited numerous problems involved with implementation. However, there are messages for

clinical services in the findings of the study which could have implications for clinical practice.

Firstly, there appears to be a mindset among clinicians that the risks of peer mentoring outweigh the benefits. However, there were no adverse events in this study and no reports of negative influences from mentors, which is in common with all the other published peer mentoring studies. Secondly, mentoring does not have to be a long-term intervention, but can be useful in the short term, potentially running concurrently with other rehabilitation treatments. The intervention in this project and several others reported in previous research have operated over three- or six-month periods.

Thirdly, peer mentoring is highly adaptable and can be tailored to the needs of individuals. The qualitative findings have highlighted numerous potential outcomes and the possibility of helping people to engage with activities that are of particular interest to them. Fourthly, this study has highlighted the difficulties with recruiting people in the early stages of recovery. However, the engagement work and published research tells us that people could be considered for mentoring at any stage of recovery and may be more able to benefit at later stages, when they have better self-awareness and insight. Therefore, clinical services could consider mentoring for patients at any time that it would best suit them, and it could be particularly helpful for people who are nearing the end of their time with a service.

It is clear that peer mentoring implementation is time and resource intensive, which is a major limiting factor in its implementation. Clinical services would need to allocate resources for mentor screening, selection and training;

matching of pairs; supervision of mentors and mentees; regular support with the organisation of meetings; and checking in for meetings. Clinical services could consider collaborating with third sector organisations, such as Headway and the Stroke Association. Furthermore, healthcare professionals should maintain an open mind about referring to external services, either for current clients or for those who will need long-term support after discharge.

The difficulties are not insurmountable. Engagement with clinical recruitment services from the early planning stages of the intervention, and information from this and other previous studies, can help to allay the fears of clinicians and improve recruitment for future services. Careful planning, informed by the findings of this and other studies, can optimise the allocation of staffing and resources specific to each service's requirements.

Finally, this study has not conducted a cost-analysis or health economic evaluation. This was not considered for the study because there was no control arm to compare with the costs of the intervention. Implementing this would have been too demanding of time and resources for this PhD study. However, attributing the costs and identifying the cost sources would be worthwhile prior to any future testing or clinical implementation. Clinical commissioners should also be consulted regarding their views on the delivery and embedding of peer mentoring, which would complement the range of professionals and service users consulted in this study.

6.8 Research Implications of the Study

The results and challenges of the study can be extremely informative for future research and there are many lessons to be learned. Importantly, three mentees

in this study stated that they would have liked a mentor with the same type of brain injury. Future studies of peer mentoring for all forms of ABI should attempt to match for condition (e.g., stroke to stroke and TBI to TBI), although mixed condition pairs can be successful, as evidenced by one pair in this project. Furthermore, the eligibility criteria of <12 months was found to be too early to recruit enough mentees. Future studies could attempt to recruit mentees at any point after injury. There is reason to believe that people can benefit more from the intervention at a later stage when they are ready and have developed a better awareness of their limitations and needs.

If peer mentoring is to be done well then it will be resource intensive and there needs to be sufficient staffing and resources in place to provide training, supervision, and ongoing support. Recruitment is a particularly important aspect of this and is extremely challenging, especially the recruitment of mentees. Recruiters should be consistently engaged with from the outset and involved in the early stages of planning the project and setting eligibility criteria. The study has also shown that speed and timeliness of recruitment of mentors and mentees is important in order to facilitate matching mentees with suitable mentors as quickly as possible. The delays with matching pairs caused two mentees to withdraw before the intervention and was a source of frustration for other participants. In future studies, potential participants should be engaged with, enrolled, matched, and started on the intervention with as few delays as possible.

Peer mentoring is an extremely adaptable and versatile intervention and is amenable to investigating many different outcomes. However, research studies should employ a clear focus and appropriate methods in order to build the

evidence base for effectiveness with their chosen outcome/s. For example, the primary effectiveness measure of this study was participation, but the chosen measure did not capture the desired information and there were no leisure activities in meetings. To investigate participation, future research should set activity goals for mentoring sessions and choose an assessment tool which measures social and leisure participation. For example, the Impact on Participation and Autonomy Questionnaire specifically relates to social and leisure activities and is closely linked to the ICF participation domain, so could be used in future studies (Cardol et al., 2001).

Researchers should be aware of the difference between proximal (short-term and/or closely connected) and distal (long-term and /or distantly connected) outcomes (in the terms used by Levy et al.) and recognise that it may not be possible to measure the impact on distal outcomes in a short-term intervention. For example, community integration may not be directly affected by mentoring, and increased leisure participation may be a long-term goal. Improvements in these areas may need to be preceded by proximal improvements in domains such as knowledge or skills (Levy et al., 2021). In short-term projects it may be more informative to assess these proximal domains. For example, mentoring could more explicitly focus on improving a mentee's knowledge about local resources or memory coping strategies and measure short-term improvement in these areas. Long-term follow-ups could then investigate whether improvements in these areas have been maintained and whether they are associated with distal outcomes such as improved quality of life.

Finally, it is possible that the benefits of peer mentoring can be assessed much more effectively by qualitative analysis than with quantitative investigation. The interviews in this study and others have revealed perceived benefits for participants that were not captured by the quantitative measures. Future studies of peer mentoring would be well-advised to always operate a qualitative strand.

6.9 Limitations

There were several limitations with the study. Firstly, the small number of participants limited the conclusions that could be drawn and the generalisability of the findings. The small pools of mentees and mentors meant that there were differences between the groups in injury types and ages, so it was not possible to match the pairs on the intended criteria. This led to partnerships which may not have been as successful as otherwise could have been expected.

The slow recruitment also led to delays in the process of matching participants, which led to two mentees withdrawing before they could be matched and begin the intervention. The delays were frustrating for those who did participate and two of the mentees may have lost some motivation and interest before their partnerships began.

There was a lack of defined structure and content in mentoring meetings. This was partly deliberate in order to allow participants the freedom to discuss issues of personal importance and to avoid putting undue pressure on them to engage in activities. However, the result was that there were no leisure activities in meetings and limited impact on participation. It would have

strengthened the design if a structured schedule, with participation-based goals, had been in place for each pair.

The intervention design did not, ultimately, have a theoretical foundation in one of the relevant psychological theories, such as self-efficacy theory (Bandura, 1977), self-determination theory (Deci and Ryan, 1985; Deci and Ryan, 2008), or transformational leadership theory (Bass, 1999). Although the previous studies using these theories informed the background for the project, having been employed in spinal injury peer mentoring research, ABI peer mentoring has only recently begun to incorporate them. I chose to focus the design of the intervention on the TIDieR elements identified by the systematic review, PPIE, and qualitative development work, and on the ICF and BCW components which informed the topic guides and qualitative analysis. While this was a strength of the study, investigating self-efficacy and/or transformational leadership could have informed more focussed outcomes and provided a better understanding of how the intervention worked (Fleury et al., 2018).

The scheduling and organisation of meetings for two of the pairs was ineffective, contributed to the early cessation of one partnership, and impaired the mentees' enjoyment. Better planning and advanced scheduling at the outset of partnerships could have avoided this.

The collection of data post-intervention was delayed, meaning there was a long gap between the ends of the partnerships and gathering the data. This could have led to results that did not accurately reflect the effectiveness of mentoring. It is also likely that the outcome measures themselves did not adequately

measure the intended outcomes, for example the CIQ and EQ-5D-5L probably did not measure the relevant elements of participation and quality of life. It would also have strengthened the project, particularly in the area of participation, if I had used a standardised measure of goal attainment, such as the GAS–Light scale (Turner-Stokes, 2009a). Instead, I used a simple, non-standardised method of asking participants to specify two to three goals. Finally, I collected the post-intervention quantitative data myself, which was a possible confounding factor and source of bias because I was known to the participants.

6.10 Strengths

A major strength of the study was the thorough recruitment efforts, despite their limited success. I used recruitment sites across the region, with service users encompassing a wide range of injury types. I engaged with the recruitment sites throughout the process, conducting visits and maintaining regular contact with the team managers. The robust recruitment methods mean that the difficulties with recruitment, particularly for mentees, are likely to be inherent with peer mentoring research and need to be accounted for and mitigated in future projects.

The design and delivery of the mentor training was a major strength of the project. All aspects of the training were acceptable for the delegates, and mentors stated that it prepared them well for their role. The design of the training drew on previous research and the findings of the development work, and utilised well-planned scheduling and a comprehensive range of information materials. I planned the training in consultation with expert professional colleagues, who reviewed the materials and provided feedback,

and conducted practise sessions with colleagues in the division. I delivered the training in partnership with a colleague who was an occupational therapist with brain injury expertise and experience of training delivery (JP).

The safety and security of the participants in the project was a significant strength. I drew on the findings of previous research and the views of professionals and service users to devise safeguarding measures which were carefully followed. All the mentors underwent DBS checks and were screened for suitability based on their performance in training. My colleague in delivering the training (JP) helped me to assess their suitability, and all potential mentors were also required to provide a reference from a rehabilitation professional they had previously worked with to confirm their suitability. All the participants in the intervention were required to provide me with the dates and times of their meetings and to contact me by telephone to confirm attendance and arrival home afterwards. I contacted the participants after meetings to discuss their progress and ask about any issues or concerns.

I conducted the qualitative aspects of the project with the assistance of other researchers, which added to the robustness of the methods. Two Masters students assisted me in devising and conducting the stroke interviews and ABI focus groups in the development phase, while another researcher, previously unknown to the participants, conducted the post-intervention qualitative interviews. Employing the support of these colleagues reduced the risk of bias in the data collection and added to the veracity of the qualitative analysis by discussing and confirming the interpretation of themes.

Finally, another key strength of the project was that it conformed closely to the MRC guidelines. I conducted a thorough systematic review which used the TIDieR framework to examine all the relevant elements of the studies I identified, and I conducted very thorough engagement work with representatives of relevant service user and provider groups. The topic guides and analysis were informed by the ICF, BCW, and the TIDieR guidelines, which provided solid foundations for designing each element of the intervention and analysing the results with regards to the important mechanisms and outcomes.

6.11 Suggestions for Future Research

A future study could begin by broadening the recruitment criteria for mentees to include people at any stage of recovery. The important criterion is that the person themselves and/or their carers and family members feel that they would benefit from a mentor. The recruitment strategy for mentees could also be broadened and allow self-referrals from online adverts on the websites and social media channels of brain injury charities. The recruitment of both mentees and mentors through local rehabilitation services should be employed again, but this time researchers should engage with the recruitment teams from the planning stage of the study and elicit their feedback on the eligibility criteria and intervention design. A broader recruitment strategy can allow for participants from outside of the local area and employ remote mentoring meetings via telephone or on Skype or Microsoft Teams, which were not widely used at the time the current intervention was devised. The intervention can then employ a combination of face-to-face, telephone, and online meetings.

Participation could be studied as an outcome by setting participation goals for meetings and also using a standardised measure of goal attainment (such as GAS-Light) and the Impact on Participation and Autonomy Questionnaire (IPAQ) (Cardol et al., 2001). Meetings could be scheduled to include doing an activity of interest twice over the course of six meetings and setting plans for how to maintain involvement in the activity after mentoring is over. Measures of self-efficacy and self-determination should be employed with mentees and mentors along with measures of mood, quality of life, self-esteem, and confidence and assessments of the impact on carers. Short-term outcomes that are amenable to immediate improvement are also recommended, such as knowledge about local services. The Peer Mentoring Questionnaire is also useful to assess the subjective impact of mentoring quantitatively, so it is recommended that researchers use it. As it is not a standardised measure, it is suggested that researchers adapt it to the aims and outcomes of their own study. It is not recommended to attempt to conduct an RCT. Instead, the quantitative aspect of the study could administer measures at a series of timepoints, e.g., at baseline, mid-intervention period, immediately post-intervention, and at 3 months, 6 months and 12 months. This would provide valuable information regarding the short-term and long-term impacts.

6.12 Conclusion

This project has provided important information on peer mentoring for people with acquired brain injury. First and foremost, there is enthusiastic interest in the potential of peer mentoring among brain injury professionals, survivors, and carers. This interest is reflected in the growing number of studies emerging

in the field. However, this study and others have encountered numerous difficulties which highlight the challenges of implementing peer mentoring.

The first significant challenge was to obtain ethical approval to conduct the intervention study. The University sponsor requested amends to the protocol and the first Research Ethics Committee application was rejected. Researchers must be aware that peer mentoring raises numerous issues regarding the safety of participants, which must be thoroughly addressed in research protocols by initiatives such as DBS checks for mentors and lone worker procedures.

One of the main challenges of peer mentoring research is recruitment (particularly of mentees), as has been shown by other TBI and stroke peer mentoring studies identified in the systematic review (Hibbard et al., 2002; Struchen et al., 2011) and conducted more recently (Hilari et al., 2021; Masterson-Algar et al., 2020). Despite pursuing multiple recruitment sources, including the NHS, social media, and local networks, only six people consented to participate as mentees and two withdrew before matching. The recruitment period had to be extended and the original criterion of people less than six months post-hospitalisation after injury had to be amended to <12 months.

The post-intervention interviews with professionals at the recruitment sites showed that clinicians may be reluctant to refer to peer mentoring interventions due to concerns about risk. Previous studies have also shown that healthcare professionals play a key role in enabling access to further rehabilitation for brain injury survivors, and that this is a complex process which goes beyond the appraisal of potential benefit (Foster et al., 2004; Lam Wai Shun et al.,

2017). This barrier to recruitment can potentially be mitigated in future studies by engaging with clinicians from the planning stage of the project to ensure their understanding and commitment. It would also help to set clear eligibility criteria and agree that clinicians will refer anyone who meets those criteria rather than making their own judgements about suitability.

Recruiting mentees in the early stages of recovery may be difficult because of a lack of eligible patients at rehabilitation services and a lack of readiness among people at this stage. It is possible that people may benefit more from peer mentoring later following injury when they feel ready and have developed greater awareness of their limitations and needs, as other researchers have also concluded (Masterson-Algar et al., 2020). Recruiting mentees at later stages of their recovery would have been successful because I was informed by some of the recruiters that several patients who could have participated were ineligible because they were beyond the <12 months criterion. I recommend that future studies recruit mentees at any point after injury and also consider allowing mentees to self-refer.

Mentors proved easier to recruit, with twelve participating in the training programme and nine completing training and consenting to become mentors. These people were extremely enthusiastic about mentoring, as were the participants in the qualitative interviews and focus groups. There appears to be a desire among many brain injury survivors to use their experiences to help others. Unfortunately, several mentor applicants were ineligible due to living outside the catchment area, so future studies could recruit greater numbers by using remote contact methods for mentoring meetings, thus eliminating the need for local mentors. Online video calling systems such as Microsoft Teams

and Zoom were not widely used when this project started but could be used for mentoring meetings in future projects.

The small pools of mentors and mentees meant it was not possible to match pairs adequately according to the pre-specified criteria, such as type of brain injury. Although one mixed-condition pair was successful and mentors said that the type of injury was not important, some mentees said that they would have preferred a mentor with the same type of injury. These contrasting views show that there are advantages to having a mentor with the same type of injury (e.g., common experiences of recovery) which are very important to many people; however, other factors, such as excellent personal rapport and common interests, can be just as important. Future researchers should attempt to match people with the same type of injury where possible, although it would be informative in a larger study to compare same-condition and mixed-condition pairs and explore their relative success. The time taken to recruit and match pairs also led to dissatisfaction among participants and the withdrawal of two mentees, meaning that future studies should match pairs and begin the intervention as soon as possible after recruitment.

In addition to the difficulties I experienced with ethical approval and recruitment, the mentoring intervention was also challenging and resource intensive to deliver. For example, the mentor training required substantial time, resources, and expense to create the content, prepare, organise, and deliver; conducting face-to-face assessments requires substantial travel and organisation; and the mentoring partnerships required ongoing communication with the participants to check on their attendance at meetings, help with organisational issues, and monitor progress. Other studies have reported similar

challenges with the resources required to support peer mentoring projects (Hilari et al., 2021; Levy et al., 2021; Masterson-Algar et al., 2020; Struchen et al., 2011). Considerable resources for supporting both recruitment and intervention delivery would need to be allocated by those commissioning peer mentoring interventions and factored into any larger study.

One PAIRS intervention design goal was to encourage participation in valued activities, thereby enhancing quality of life and community integration. However, the activities in the mentoring sessions mainly involved talking in coffee shops or taking brief walks. There may be many reasons for this, including safety, convenience, lack of common interests in activities, and cognitive and physical impairments making physical activities difficult or inconvenient. However, this study allowed participants to choose whether they wanted to pursue activities and what those activities would be, thereby making it easier for participants to pursue the most convenient and accessible options. Future studies may benefit from a more structured and focussed approach to studying peer mentoring and activity participation, such as making activities a compulsory element of mentoring meetings and focussing on specific activities. Such an approach has proven successful for SCI peer mentoring in helping people with using motorised wheelchairs (Best et al., 2016).

Participants encountered numerous difficulties with arranging and attending meetings. Some of these were possibly related to cognitive impairments such as memory problems, which made planning and organising meetings difficult and meant that I often needed to help. Furthermore, physical impairments made travel and physical activities difficult. In some cases, inefficient communication between pairs led to misunderstandings and difficulties with

arranging meetings. These findings are consistent with a peer coaching after stroke project in Wales in 2015, in which only one pair met the required six times (Masterson-Algar et al., 2020). The problems with arranging meetings and the perceived lack of compatibility between some pairs due to their different types of injury were the main reasons for two of the pairs ending the intervention early. As this and other studies have shown, it is difficult to maintain partnerships for a sustained period of time. This is a major disadvantage of peer mentoring and makes it very difficult to measure its effectiveness. Studies which have organised meetings at set times and venues on a weekly or fortnightly basis have been successful in achieving the full quota of meetings (Coles and Snow, 2011; Fraas and Bellerose, 2010). This approach could be considered in future studies, as could remote contact methods such as telephone and online video calling. This would remove the stress and inconvenience of organisation and travel.

There has been very little quantitative evidence of effectiveness from previous studies of brain injury peer mentoring and the small sample size in this study meant that no further clear evidence was obtained. Participation was the primary outcome in this study, assessed using the CIQ (Willer et al., 1993), participants' goals and the Peer Mentoring Questionnaire. Although mentees improved slightly on the CIQ Social Integration and Productivity subscales, they worsened on the Home Integration subscale. Previous studies of ABI mentoring have also had limited success with participation as an outcome, either using the CIQ (Hilari et al., 2021; Levy et al., 2021) or other measures (Struchen et al., 2011; Fraas and Bellerose, 2010; Hanks et al., 2012). These results suggest both that it is difficult for peer mentoring to improve

participation and that it is difficult to define and measure what we mean by participation. For example, the CIQ does not appear to be an appropriate measure for this type of study.

There were indications from the DASS-21 that some mentees experienced worsening anxiety and stress. It is unknown whether this was a direct result of the intervention, but this evidence and the findings of a previous study (Struchen et al., 2011) suggest that mentoring may have this effect in some cases, possibly by raising mentees' insight of their condition and awareness of their long-term difficulties. The results show that depression, anxiety, and stress are important factors to assess in peer mentoring studies and that the DASS-21 is sensitive to change in the participant group and is an appropriate measure to use.

From a more positive perspective, there were decreases in carer burden for all three carers on the CBS, suggesting a possible impact of peer mentoring on relieving carer burden which requires further investigation. Future studies should attempt to recruit a larger sample of carers, to ask questions about carer burden in qualitative interviews, and to administer measures during the intervention and immediately afterwards in order to analyse the impact of mentoring on carers more clearly.

Overall, the lack of clear quantitative changes for mentees adds to the evidence that peer mentoring is difficult to assess quantitively and different outcomes and measures may be needed in future studies. It is possible that focusing on specific activities and participation-related goal attainment may be informative, along with other outcomes reflecting the perceived benefits of mentoring

revealed by the embedded qualitative study; for example, self-esteem, using a measure such as the Rosenberg Self-esteem Scale (Rosenberg, 1965), or self-efficacy using a measure such as the Perceived Control Scale for Brain Injury (Malec et al., 2010).

Despite the feasibility challenges and the lack of quantitative evidence for effectiveness, there were clear signs of the advantages and benefits of peer mentoring. The qualitative findings suggest that mentees found it reassuring and informative to talk to a fellow brain injury survivor, and that mentors gained enormous satisfaction from using their experience in a positive way. The mentor training was successful, enjoyable, and rewarding for all involved and mentors all said that it prepared them well for their roles. The systematic review (Chapter Two), the qualitative interviews and focus groups (Chapter Three), and the post-intervention interviews (Chapter Five) all provide evidence to corroborate the findings from spinal injury mentoring research regarding the key overarching outcomes of peer mentoring and the important traits of peer mentors. The key outcomes fit those found by Rocchi to be adaptation, connection, growth, hope for the future, knowledge, and participation (Rocchi et al., 2021). The key traits of mentors fit within those found by Gainforth to be competencies, personality characteristics, emotional states, outlook, reason for mentoring, and role modelling (Gainforth et al., 2019). This study has also provided important information regarding matching criteria, showing that consideration needs to be given to type of injury, geographical location, interests/hobbies, age, and gender, in addition to Gainforth's key criteria: mentor's knowledge matches mentee's needs; time availability; outlook and approach; knowledge about community-based

resources; similar lifestyle goals that the mentee wants to achieve/experience; and experience with similar challenges that the mentee might encounter (Gainforth et al., 2019).

It is also important to note that the demographic characteristics of the sample were not representative of the general population or of the brain injury population. The mean age of the mentees (64.25) was high compared with the large proportion of younger people who sustain brain injuries, particularly TBIs. This could have had an impact regarding the social and leisure participation needs of the mentee participants, which were likely to be different to those of young survivors. It is likely that younger mentees would have been more willing to participate in activities. The lack of ethnic minority representation is also important when considering the outcomes of the study because there is no information regarding cultural differences in the needs of participants or the matching of pairs. This was also an issue with the lack of diversity among participants in the development work, which detracts from the broad relevance of the intervention design and its generalisability. This lack of diversity is a common problem in healthcare research (Shea et al., 2022; Etti et al., 2021) and has led the National Institute for Health and Care Research (NIHR) to develop its INCLUDE framework to encourage more inclusive research. Future studies should make positive efforts to recruit participants across a broad range of age groups, with particular focus recruiting younger people.

Peer mentoring has great potential as an intervention for brain injury survivors. It offers flexibility and adaptability to individual requirements and allows each mentee to pursue their own goals and interests. The mode and style of delivery

can also be adapted to individual needs and circumstances. However, this adaptability and the necessity of delivering it differently to each mentee also means that peer mentoring is difficult to standardise in a way that its effects can be quantitatively measured in large studies, such as RCTs.

The personal experience of mentors is highly valued and provides a different form of support to that offered by professionals and loved ones. However, recruiting, matching, maintaining adherence, supervising, and measuring outcomes are challenging. There are issues of risk and safeguarding which need to be considered carefully (and may add to the challenge of recruitment) but there were no adverse events in this or other similar studies, which should reassure future researchers, sponsors, and recruiters. It is also difficult to target long-term goals such as enhanced participation and social integration in a short-term intervention with a limited number of meetings.

The quality of research in the field of brain injury peer mentoring is improving all the time and there is the potential for creating excellent services in the future. The positive attitudes of the clinicians I spoke to for the study also suggest that integrating mentoring services with clinical rehabilitation is a genuine possibility. Doing so would mitigate many of the safeguarding and supervision problems, but it is important that clinicians do not overestimate the risks involved. Future research projects should ensure sufficient staffing and resources for the many elements of peer mentoring. A large study should employ different methods to those used here, such as broadening the inclusion criteria to maximise participant numbers, using a small team of researchers, and allowing remote contacts for mentoring meetings.

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Appendix 1: PRISMA Checklist

TITLE		
Title	1	Identify the report as a systematic review, meta-analysis, or both.
ABSTRACT		
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.
INTRODUCTION		
Rationale	3	Describe the rationale for the review in the context of what is already known.
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).
METHODS		
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.

Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	

Appendix 2: Systematic Review Search Strategy

The following is an example of the search strategy employed in the systematic review. The example presents results from the original search in October 2016 and the updated search in October 2022.

Ovid MEDLINE(R) 1946 to Present and Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations

Exp meningitis/ OR exp encephalitis/ OR exp stroke/ OR exp brain infarction/ OR exp cerebral infarction/ OR exp brain neoplasms/ OR exp hydrocephalus/ OR exp hypoxia, brain/ OR exp carbon monoxide poisoning/ OR exp brain abscess/ OR exp Neurotoxicity Syndromes/ OR exp brain diseases/ OR exp Intracranial Aneurysm/ OR exp Brain Edema/ OR exp Cerebrovascular Disorders/ OR exp Brain Injuries/ OR exp brain injury, chronic/ OR exp Diffuse Axonal Injury/ OR exp craniocerebral trauma/ OR exp intracranial hemorrhages/ OR exp brain concussion/ OR exp Brain Ischemia/ OR exp Hematoma, subdural/ OR exp Subarachnoid Hemorrhage/ OR exp Basal Ganglia Cerebrovascular Disease/ OR exp cerebral hemorrhage/ OR exp Brain Hemorrhage, traumatic/ OR exp brain damage, chronic/

Search results 28.10.2016: 1,222,995; 18.10.2022: 1,514,165.

OR

brain injur*.mp. OR head injur*.mp. OR head trauma.mp. OR craniocerebral trauma.mp. OR brain trauma.mp. OR diffuse axonal injur*.mp. OR concussion.mp. OR brain damage.mp.

Search results 28.10.2016: 127,387; 18.10.2022: 173,698.

OR

meningitis.mp. OR encephalitis.mp. OR stroke*.mp. OR subarachnoid h?emorrhage.mp. OR sub-arachnoid h?emorrhage.mp. OR cerebral h?emorrhage.mp. OR intracranial aneurysm.mp. OR cerebrovascular disorder$.mp. OR cerebrovascular disease$.mp. OR intracranial h?emorrhage.mp. Or brain h?emorrhage.mp. OR brain isch?emia.mp. OR subdural h?ematoma.mp. OR sub-dural h?ematoma.mp. OR brain isch?emia.mp. OR brain neoplasm*.mp. OR brain tumo?r*.mp. OR brain cancer.mp. OR hydrocephalus.mp. OR hypoxic brain injur$.mp. OR anoxic brain injur$.mp. OR carbon monoxide poisoning.mp. OR brain abscess.mp. OR neurotoxicity syndrome$.mp. OR brain disease$.mp. OR brain edema.mp. OR brain oedema.mp. OR encephalopath$.mp. OR toxic encephalopath$.mp. OR brain disorder$.mp. OR brain infarct$.mp. OR cerebral infarct$.mp.

Search results 28.10.16: 689,972; 18.10.2022: 945,148.

OR

(injur* OR damage OR trauma* OR lesion* OR damage* OR contusion OR destruction OR fracture* OR wound OR h?emorrhag* OR h?ematoma OR bleed* OR infarct$ OR isch?em$ OR occlusion OR apoplex$ OR embolism OR edema OR swell* OR infect* OR virus OR deprivation OR hypox* OR anox* OR pressure) ADJ3 (brain* OR head* OR skull OR crani$ OR intracranial OR cereb$ OR diffuse axonal).mp.

Search results 28.10.16: 356,942; 18.10.2022: 475,969.

OR

(brain* or glioma or astrocytoma or oligodendro$ or choroid plexus or neuroepithelial or neuronal or pineal OR mening$) ADJ3 (neoplasm$ or tumo?r or carcinoma or cancer).mp.

Search results 28.10.2016: 121,274; 18.10.2022: 161,302.

Total search results 28.10.2016: 1,481,636; 18.10.2022: 1,920,211.

AND

exp mentors/ OR peer support*.mp. OR mentor*.mp. OR peer coach*.mp. OR peer counsel*.mp. OR peer partner*.mp. OR peer tutor*.mp. OR peer train*.mp. OR peer educat*.mp. OR peer teach*.mp.

Search results 28.10.2016: 19,538; 18.10.2022: 37,385.

Overall combined totals 28.10.16: 253; 18.10.2022: 613.

Appendix 3: TIDieR Checklist

The TIDieR (Template for Intervention Description and Replication) Checklist*:

Information to include when describing an intervention and the location of the information

Item number	Item	Where located **	
		Primary paper (page or appendix number)	Other † (details)
	BRIEF NAME		
1.	Provide the name or a phrase that describes the intervention.	_____	_____
	WHY		
2.	Describe any rationale, theory, or goal of the elements essential to the intervention.	_____	_____
	WHAT		
3.	Materials: Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g. online appendix, URL).	_____	_____
4.	Procedures: Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities.	_____	_____
	WHO PROVIDED		
5.	For each category of intervention provider (e.g. psychologist, nursing	_____	_____

5.	For each category of intervention provider (e.g. psychologist, nursing assistant), describe their expertise, background and any specific training given.		
	HOW		
6.	Describe the modes of delivery (e.g. face-to-face or by some other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group.		
	WHERE		
7.	Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.		
	WHEN and HOW MUCH		
8.	Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose.		
	TAILORING		
9.	If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when, and how.		
	MODIFICATIONS		
10.‡	If the intervention was modified during the course of the study, describe the changes (what, why, when, and how).		
	HOW WELL		
11.	Planned: If intervention adherence		

11.	Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them.		
12.‡	Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.		

Appendix 4: Systematic Review Study Synopses

Randomized Controlled Trial of Peer Mentoring for Individuals with Traumatic Brain Injury and their Significant Others. 2012. Hanks, R. et al.	
Item 1: Brief name	Peer mentoring
Item 2: Why	Aims of the intervention are to improve (1) emotional wellbeing; (2) post-TBI quality of life; and (3) community integration.
Item 3: What: materials	Mentor training manual.
Item 4: What: procedures	Mentors participated in 20 hours of training, and all mentors were trained at the same time. Interactive training consisted of (1) modelling interviewing skills with a supervisor and fellow trainees; (2) telephone role playing; (3) discussion of what is and what is not mentoring; (4) communication skills and active listening; and (5) certificate of completion and group photo. Mentors arranged for a meeting within 2 weeks of initial contact. Discussions in mentoring sessions were focused on 3 main areas: (1) emotional well-being; (2) post-TBI quality of life; and (3) community integration, and this was accomplished by the mentors providing social and emotional support, helping the mentee gain access to community resources, and discussion of any topics related to TBI or caregiving that the mentee wanted to discuss.
Item 5: Who provided	Mentor candidates were evaluated on social competency (rated by supervisory/training staff), willingness to talk openly about disability and life experiences, motivation and commitment to participation. Mentors had weekly in-person supervision from a psychologist, a nurse, and community outreach coordinator. These supervisors were available for 24-hour emergency assistance.
Item 6: How	Mentor training: All mentors were trained at the same time. Interactive training involved modelling interviewing skills, telephone role playing, discussion of what is and is not mentoring, communication skills and active listening. Intervention: Mentors arranged for a meeting within 2 weeks of initial contact and were requested to meet and/or talk via telephone at least weekly for the first month, biweekly for the next 2 to 3 months, and then monthly for the remainder of the first year. Contact more frequent than these minimum

	guidelines was encouraged as appropriate. Discussions in mentoring sessions were focused on three main areas: (1) emotional well-being; (2) post-TBI quality of life; and (3) community integration, and this was accomplished by the mentors providing social and emotional support, helping the mentee gain access to community resources, and discussion of any topics related to TBI or caregiving that the mentee wanted to discuss.
Item 7: Where	Community or telephone.
Item 8: When and how much	Weekly for the first month, biweekly for the next 2 to 3 months, and then monthly for the remainder of the first year. Contact more frequent than these minimum guidelines was encouraged as appropriate.
Item 9: Tailoring	Discussions in mentoring sessions were tailored to the needs of each mentee.
Item 10: Modifications	None described.
Item 11: How well: planned	Not described.
Item 12: How well: actual	Not described.

Making connections after brain injury: development and evaluation of a social peer-mentoring program for persons with traumatic brain injury. 2011. Struchen, M. et al.	
Item 1: Brief name	Social peer mentoring programme
Item 2: Why	Improving social integration in adults with TBI seeking assistance with meeting people and increasing their social participation.
Item 3: What: materials	Training: Social mentor training manual – 'Making connections after brain injury: A guide for social peer mentors' provided to all mentors. Intervention: Social mentors were also asked to complete a monthly mentor log sheet, which tracked mentoring activities throughout the mentoring period.
Item 4: What: procedures	Training: Initial training was conducted in two 2-hour group sessions led by a neuropsychologist and a consumer representative with TBI who was part of the research team. This training was supplemented by a written manual and by

	additional booster training as needed. Group training sessions included didactic presentation, discussion, and role-play of specific skill-building activities. Intervention: During the initial contact, SPMs were asked to introduce themselves and to set up an initial outing with their PPs. After the initial contact, additional contacts could be initiated by either the SPM or the PP; however, the SPM was responsible for ensuring that each respective PP participated in a minimum of 2 outings with the mentor per month. The goal of outings was to foster increased social networking for the PP through introductions to people, activities, and resources within the partner's own community.
Item 5: Who provided	Training: Initial training was led by a neuropsychologist and a consumer representative with TBI. Intervention: A committee consisting of neuropsychologists and neuropsychology fellows. On-call therapist for mentors. All participants sustained a medically documented TBI and were community-dwelling. Only individuals aged 18 or older who were no longer participating in a comprehensive rehabilitation program were eligible for the study. Good social integration functioning (minimal score of 100 on CHART-SF social integration sub-scale) and social participation. Understanding of relationship issues, the role of a mentor and potential risk factors. Criminal background check and three letters of reference.
Item 6: How	Training: Group face-to-face sessions. Intervention: Face-to-face.
Item 7: Where	Community venues
Item 8: When and how much	Minimum of two outings per month for three months.
Item 9: Tailoring	The activities and discussions in meetings were tailored to the needs of each mentor, as was the frequency of meetings beyond the minimum requirement.
Item 10: Modifications	None described.
Item 11: How well: planned	Not described.
Item 12: How well: actual	Not described.

Peer support in the community: initial findings of a mentoring program for individuals with traumatic brain injury and their families. 2002. Hibbard, M. et al.	
Item 1: Brief name	TBI Mentoring Partnership
Item 2: Why	To address both the acute and long-term adjustment needs of individuals with TBI and their family members.
Item 3: What: materials	Mentor training manual.
Item 4: What: procedures	Training: At full-day mentor training workshops mentors received training focused on enhancing their communication, listening, and advocacy skills and increasing their knowledge of TBI and community resources. Intervention: Once the mentor and partner are matched, the project coordinator links the mentor with the partner, and the partnership is begun. In the TBI-MPP, TBI "veterans" were matched with individuals with TBI or family members to provide emotional support, knowledge about TBI and resources, and advocacy skills. Contact is predominantly by telephone with some face-to-face contacts.
Item 5: Who provided	Training and admin: Research and Training Centre on Community Integration for Individuals with TBI (RTC) and Brain Injury Association of New York State (BIANYS). Two experienced project co-ordinators. Intervention: Two experienced project coordinators to oversee the clinical administration of the program. The project coordinator provides ongoing technical assistance to mentors by telephone for the duration of each partnership. Criteria for mentor selection included: 1) a willingness to volunteer time and energy needed to provide support to others in need after TBI; (2) a motivation to "help others" and "give back something" and "be there for people who are where I was"; (3) successful personal adjustment to the challenges of living with a TBI; (4) adequate insight into personal limitations and strengths; (5) an absence of current serious psychiatric problems; (6) an ability to listen and empathize and (7) an ability to inhibit personal responses and views or opinions when necessary.
Item 6: How	Mentors talk with mentees and provide emotional support, information about TBI and resources, and advocacy support.
Item 7: Where	Predominantly telephone with some face-to-face contact at community venues.

Item 8: When and how much	Duration and frequency are entirely up to the participants.
Item 9: Tailoring	Content and frequency of meetings are tailored to each individual.
Item 10: Modifications	None described.
Item 11: How well: planned	NA – retrospective evaluation
Item 12: How well: actual	NA – retrospective evaluation

A model system of traumatic brain injury peer support importance, development and process. 1996. Moreci, G.	
Item 1: Brief name	Traumatic Brain Injury Peer Support Volunteer Programme
Item 2: Why	Provide information, support and hope at the acute stage.
Item 3: What: materials	Monthly calendars with scheduled peer support visits; weekly documentation regarding each patient and family to be visited; a manual of procedures for filling out all essential written documentation, summaries of programme activities, a volunteer job description, the grief process handouts, active listening handouts, communication handouts, and TBI education handouts.
Item 4: What: procedures	Peer supporters visit the rehabilitation centre in teams of two, three nights each week for two hours. The peer supporters provide a listening ear and a sensitive awareness of TBI issues. Annual training seminars and ongoing bi-monthly informal training meetings. Trained in grief process, active listening, communication, hospital procedures and brain injury education. Bi-monthly training meetings.
Item 5: Who provided	Peer supporters were carefully screened by private interview, references and a resume. Experience with TBI, positive references and personal attributes such as genuineness, ability to listen, appropriate empathy and a positive regard for people were required. Programme co-ordinator monitors peer supporters, guides them on the purpose of the visits and structures program activities. The programme co-ordinator is responsible for the delegation of tasks and the co-ordination of task completion.

	Training delivered by hospital neuropsychologist and experts in grief process, active listening, communication, hospital procedures and brain injury education.
Item 6: How	Patients are able to release emotions without being interrupted or judged. The peer supporter can also be available to discuss brain injury with the family in detail. Peer Supporters also make phone calls to offer support to individuals and their families who have left the rehabilitation unit. The Peer Supporters also encourage the persons visited to attend group sessions as well as receive individual peer support visits.
Item 7: Where	Face-to-face on a rehabilitation unit in San Jose, California. Follow-up calls by telephone.
Item 8: When and how much	One visit on the rehabilitation unit for no more than approximately 30 minutes. Subsequent telephone follow-ups but no set guidelines on number or duration of calls.
Item 9: Tailoring	Content of discussions are tailored to each individual's needs.
Item 10: Modifications	None described.
Item 11: How well: planned	NA – description of service
Item 12: How well: actual	NA – description of service

An effective community-based mentoring program for return to work and school after brain and spinal cord injury. 2012. Kolakowsky-Hayner, S., et al.	
Item 1: Brief name	The Back on Track to Success Mentoring Programme
Item 2: Why	Improve the ability of an individual with disabilities to access and maximally utilize the services and programs that are available in the community.
Item 3: What: materials	Enrolment and assessment forms.
Item 4: What: procedures	Each mentee was matched with a community-based mentor for age, gender, disability type, location, interests, etc. Mentors underwent a training curriculum and refresher sessions throughout the program under the facilitation of a Rehabilitation Psychologist and the Program Coordinator.

	Training was based on the structure of the traumatic brain injury (TBI) and spinal cord injury (SCI) Peer Support Program volunteer training at our facility. Mentor/mentee relationships were required to have a minimum of 3 contacts per month through in-person, telephone, or electronic mail methods.
Item 5: Who provided	Staff: Two physicians, a Program Coordinator, a Program Assistant, a Vocational Counsellor, and a Rehabilitation Psychologist. Mentors: Minimum 2 years post injury. High level of acceptance and successful integration into community (e.g., working or post-secondary education).
Item 6: How	Mentor/mentee relationships were required to have a minimum of 3 contacts per month through in-person, telephone, or electronic mail methods.
Item 7: Where	Community, face-to-face, telephone or email contacts.
Item 8: When and how much	Mentor/mentee relationships were required to have a minimum of 3 contacts per month through in-person, telephone, or electronic mail methods.
Item 9: Tailoring	Discussions in meetings were tailored to individual mentees.
Item 10: Modifications	None described.
Item 11: How well: planned	Not described.
Item 12: How well: actual	Not described.

Applying the principles of peer mentorship in persons with aphasia. 2011. Coles, J. and Snow, B.	
Item 1: Brief name	The Aphasia Mentorship Programme
Item 2: Why	To enhance self-confidence and self-worth through communication with a peer.
Item 3: What: materials	Compilation of ideas for conversation starters for mentors. Future mentees are given a basic orientation packet to the programme. This contains a description of the role of a mentor, a fact sheet about the programme, and an information sheet to complete with the referrer.

Item 4: What: procedures	Training: Mentors thoroughly trained by SLPs on effective ways to communicate with others living with aphasia. Training was completed through both auditory and written guides and videos followed by discussion/demonstration with the facilitators. Through self-analysis, mentors also learned their optimal method of communicating with others. The mentors and facilitators brainstormed on ideas for initial conversation starters, which were compiled and given to each mentor as a resource. Intervention: Mentors offer emotional support by sharing their thoughts and feelings with a non-judgmental receptive ear, encouraging their mentees to embrace life and helping mentees increase their feelings of self-worth.
Item 5: Who provided	Mentors defined as: 1) someone who listens to and shares knowledge and life experiences with other stroke survivors; 2) someone who is able to relate to communication difficulties following a stroke. the programme emphasised that a mentor should embrace the following qualities and characteristics – volunteer, guide, encourager, role model, advisor, sounding board, and confidant. Staff: Programme facilitated by three speech and language pathologists (SLPs). Programme delivered by three male mentors, all having experienced aphasia after stroke. Mentors involved in development of the programme. Hospital and regional outpatient staff are educated about the programme and refer potential mentees to the facilitators.
Item 6: How	Face-to-face.
Item 7: Where	Initial meeting in hospital or regional rehabilitation outpatient site. Future meetings at times and locations agreed by participants (e.g. hospital, local restaurant, coffee shop or library).
Item 8: When and how much	Weekly one-hour meetings for eight weeks. Some flexibility regarding eight-week duration according to individual preference.
Item 9: Tailoring	Content of meetings tailored to the needs of mentees.
Item 10: Modifications	The programme was continually improved and expanded.
Item 11: How well: planned	Not described.
Item 12: How well: actual	Not described.

Mentoring programme for adolescent survivors of acquired brain injury. 2010. Fraas, M. & Bellerose, A.	
Item 1: Brief name	Mentor programme for adolescents with acquired brain injury
Item 2: Why	To provide social support to youth survivors of ABI while simultaneously increasing the social connections of adult survivors.
Item 3: What: materials	None reported.
Item 4: What: procedures	Training: Mentor trained and supervised by programme staff and one of the researchers (AB). Issues related to socialization, brain injury education, community resources and emotional adjustment. Intervention: During the 10-week programme, the mentor and the adolescent met one day a week from 9:30am until 2:00pm. The mentor met with the adolescent several times during the day to provide support, have lunch, play board games and discuss issues of mutual interest, such as sports and leisure activities.
Item 5: Who provided	Mentor: Inclusion criteria: a willingness to provide support to a young survivor of brain injury; (2) an absence of psychiatric or behavioural problems; (3) insight into personal strengths and limitations; (4) gender matched with the adolescent; (5) shared common interests with the adolescent; (6) an ability to listen and empathize; and (7) motivation to help others or 'give back something'. Staff: Group activities at the centre were facilitated by centre staff, community volunteers and student interns. Programme staff and researchers trained the mentor.
Item 6: How	Face-to-face.
Item 7: Where	Community-based Health and Wellness facility.
Item 8: When and how much	9:30am – 2pm one day per week for 10 weeks.
Item 9: Tailoring	Content of discussion and nature of activities were tailored to the mentee.
Item 10: Modifications	None described.

Item 11: How well: planned	Not described.
Item 12: How well: actual	Not described.

Peer support for stroke survivors: a case study. 2014. Kessler, D., Egan, M. & Kubina, L.	
Item 1: Brief name	Individual peer support for stroke survivors
Item 2: Why	Provide hope to newly diagnosed stroke survivors, decrease feelings of stigma and isolation, and offer information about post-stroke community services.
Item 3: What: materials	Peer supporter diaries.
Item 4: What: procedures	Training and supervision: Training consists of a combination of six hours of in-class group education provided by the Executive Director and Logistics Coordinator, a two-hour orientation to the hospital, and four to six individual sessions shadowing the Visit Coordinator as she carries out peer support visits. In-class training covers procedures, roles and appropriate topics of discussion, while shadowing provides opportunity for practice of routines and development of communication skills through modelling and feedback. Intervention: The peer supporters conduct their visits working in pairs, these pairs being matched to complement each other's strengths and degree of disability. The initial visit is designed to provide a message of hope; the length of this visit is approximately ten minutes. Subsequent post-discharge telephone visits are made to the stroke survivor or care partner at one, three, six, nine and twelve months. The objective of these calls is to provide on-going support, as well as information related to living with stroke and community resources. The length of these telephone visits varies between 5 and 60 minutes.
Item 5: Who provided	Peer supporter stroke survivors. Staff: Programme co-ordinator, logistics co-ordinator, visit co-ordinator.
Item 6: How	Face-to-face.
Item 7: Where	Acute hospital stroke ward. Follow-up telephone calls.

Item 8: When and how much	Initial visit is approximately 10 minutes. Follow-up telephone calls at one, three, six, nine- and twelve-months post-discharge last from 5-60 minutes.
Item 9: Tailoring	The content of visits and calls was tailored to the needs of stroke survivors.
Item 10: Modifications	Peer supporters had difficulty organising and managing follow-up calls, so the majority of these were conducted by the programme co-ordinator.
Item 11: How well: planned	It was intended that all new stroke survivors on the ward would receive a visit and that those visited in hospital would receive follow-up calls. The visits were intended to provide hope and informational, affirmational and emotional support.
Item 12: How well: actual	Not all new survivors on the unit were visited. 82% of those receiving visits in hospital were contacted for follow-up calls.

Appendix 5: PPIE Meeting Schedules

EXPERT PANEL AGENDA

26TH June 2015, 10 to 1pm Lakeside Arts Centre, University Park Campus, University of Nottingham

Aim for the workshop:

To co-design a peer coaching intervention relevant to our service and setting.

Activity		Purpose
10am Refreshments		
Who is in the room?		For us to 'meet and greet', sharing our interests in peer coaching and this study.
Success criteria		How would we define whether a peer coaching intervention was successful? *In this activity we will be working individually, and then in groups to identify shared success criteria, and to explore divergent views.*
What can peers bring to peer support?		What are the experiences, knowledge and skills that peers can bring to peer coaching? Where do they complement what professionals and others bring to support life after TBI? *In this activity we will be working in groups, and then constructing a shared map of contributions.*
12pm Working Lunch	What would a peer support interaction look like?	Who is involved? What is happening? Where is it happening? Where are other 'interested parties'? Who might be influencing this? *In this activity we will again be working in groups, and then feeding back to the whole group.*
	Challenges and moving forward	Drawing on our discussions in the workshop, what might be the challenges we might face in moving forward, and what strategies can we use to overcome these? *This activity will be a full group discussion.*

EXPERT PANEL AGENDA

6TH July 2015, 10-1, Arts Centre Nottingham University

Aim for the workshop:

To co-design a peer coaching intervention relevant to our service and setting.

Activity	**Overview**
Reconnecting who is in the room	A brief opportunity to reconnect with those present.
Revisiting the rich pictures	A brief opportunity to add to or amend rich pictures that describe the potential nature of a peer coaching encounter.
The People in Peer Coaching Making and breaking connections	In this part of the workshop, we will concentrate on how the peer and coachee can make personal connections throughout a peer coaching intervention. Examples might include what personal information is shared, when and how. *To catalyse thinking we will use an 'interview' with Patri Masterson from the Bangor project, as the stimulus for group discussions and feedback.*
Programme underpinnings	Patri will give a *brief overview* of some of the ideas that are embedded in the Bangor programme. This will explain why the programme is structured as it is, and will be followed by a *whole group Q&A*. This will help provide focus for the two remaining activities.
The Focus of Peer Coaching Developing the goal	This section of the workshop will concentrate on how the focus of the peer coaching is created and sustained. *We will listen to a short presentation, and have an opportunity to try out some of the Bangor tools, as the basis for whole group discussions.*
LUNCH	
The Process of Peer Coaching Getting and maintaining momentum	This section of the workshop will focus on potential strategies that give direction and momentum to peer coaching. *We will use some of the tools and techniques from the Bangor programme as a focus for discussions on tables, with feedback to the whole group.*
Evaluation and wrap up	Whole group discussion.

EXPERT PANEL AGENDA

16TH July 2015, 10-1, Arts Centre Nottingham University

Aim for the workshops:

To co-design a peer coaching intervention relevant to our service and setting.

Activity	**Purpose**
Reconnecting who is in the room (15 minutes)	An opportunity to reconnect with those present, and to explore the scope of our peer coaching intervention.
Identifying a shared implementation strategy (25 minutes)	This activity will consider a prototype model for implementing peer coaching, identifying the challenges we have identified so far. *The whole group will discuss and adapt a prototype model, as the basis for our on-going work.*
Exploring risk (30 minutes)	Risk is a part of everyday life, and something that has been identified as a complex issue for peer coaching intervention. This part of the workshop will explore this in more depth, highlighting implications for our work together. *Individual and whole group activities exploring risk from our own, and others' perspectives.*
Co-design groups (25 minutes each)	Building on the prototype model (above), we will have an opportunity to contribute to two small groups working to address implementation issues identified in the earlier workshops: **1. A person specification for the peers** **2. How people access the peer coaching intervention** **3. The scope of peer coaching** **4. Support for the peers** **5. Governance and risk management** *Co-design groups with rapid feedback.*
LUNCH (20 minutes)	With an opportunity to address any outstanding issues.
Reflections on the co-design process (30 minutes)	Moving away from the peer coaching intervention, this final activity will explore how the co-design process has worked, identifying what's been easy / difficult, and how we would work differently in the future. *Whole group discussion.*

Appendix 6: Carer Recruitment Advert

Carers' views wanted for University of Nottingham research project

Peer mentoring and returning to activities after brain injury

A PhD researcher at the University of Nottingham would like to interview carers of people with acquired brain injury (whether traumatic brain injury, stroke or any other cause).

The project is investigating peer mentoring as a way of helping people with brain injury participate in activities. Peer mentoring involves a person with a brain injury helping someone with a more recent injury using the experience and knowledge they have gained.

We would like to know what carers think about peer mentoring and the issues affecting participation in activities after brain injury.

'Carer' could mean a spouse or partner of someone with a brain injury, or other family member or friend.

The interviews can be done by telephone and wouldn't take much of your time. Your help can really contribute to our understanding of the issues.

If you are interested in taking part, please contact Richard Morris at r.morris@nottingham.ac.uk. Alternatively, call 0115 823 0274.

Appendix 7: Information Sheet for Carers

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

This research is part of a PhD project investigating peer mentoring after acquired brain injury (ABI). Peer mentoring involves partnering two people with brain injury together. The idea is that an experienced brain injury survivor (mentor) can help a less experienced survivor to adapt to life after brain injury. The mentor could help with many of the challenges brain injury presents.

We are particularly interested in whether peer mentors can help people return to participation in personally valued activities. This is because many people with a brain injury stop doing the things they used to enjoy before their injury. They can also find themselves seeing less of their friends. We want to find out if people with brain injuries who have overcome these problems can help others enjoy a fulfilling leisure and social life. In order to do this we are designing a peer mentoring service which will be tested at a later stage of the PhD project.

At this stage of the project we want to interview carers and close family members of people with ABI. This is so we can learn what you think are the most important outcomes of peer mentoring service and how you think it should be designed.

Why have I been invited?

You are being invited to take part because you are a 'carer' of someone with an acquired brain injury. For these purposes, 'carer' can mean a spouse or other close family member. By ABI we mean someone has sustained an injury to the brain after birth by any means, such as traumatic brain injury, stroke, brain tumour, meningitis, encephalitis or many other ways. We are inviting 5-10 people like you to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to participate you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen to me if I take part?

If you decide to take part the lead researcher will ask you to sign a consent form, which can be sent to you via your preference of post or email. When we receive your signed consent form the researcher will contact you to arrange an interview at a mutually convenient time.

The interview will be conducted by telephone unless you would prefer to meet face-to-face, in which case the researcher will try to make suitable arrangements. Interviews should take approximately 30-45 minutes. If you would like time to think about the questions then we can send them to you in advance.

The interviews will be 'semi-structured', which means that the interviewer will use a series of questions as a topic guide but will not necessarily stick rigidly to these questions. Rather the questions will be used in order to explore your views of key subject areas.

The interview will be recorded by digital voice recorder and then transcribed into text form by the researcher or a professional transcription service. All personally identifiable information will be anonymised when the interviews are transcribed and this information will be kept securely at the University of Nottingham.

The interview can be stopped at any time you like and you do not have to complete it if you don't wish to. You will not be required to share any personal information about yourself or your loved one that you don't wish to.

Should any issues of concern arise or something reportable is revealed then the researcher will discuss the appropriate course of action with their supervisors. If necessary, the appropriate authorities will be informed.

Expenses and inconvenience allowance

Participants will not be paid an inconvenience allowance to participate in the study. If you specifically require a face-to-face meeting which incurs travel expenses then the University may be able to reimburse some or all or the costs. You can discuss this further with the researcher if necessary.

What are the possible disadvantages and risks of taking part?

We do not expect to be there are any disadvantages or risks to you. We will do our best to arrange the interview at a time and in a format to suit you. You will not be required to share any personal information you are in any way uncomfortable with and you can decline to answer some of the questions if you wish. However, there is always a possibility that discussing your loved one's brain injury could raise issues you find upsetting. If this is the case you can find details of people and organisations you can contact for advice and support at the end of this information sheet.

What are the possible benefits of taking part?

The information you provide during the interview will help us to design and test a peer mentoring service to help people return to personally valued activities after acquired brain injury. This will help us to demonstrate the feasibility of such a service and also help similar projects in the future to learn from our experiences.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, some of the data collected will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the institution will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

The audio recordings of the interviews will be uploaded to a secure drive on the University of Nottingham server and then deleted from the digital voice recorder. The recordings will then be transcribed to text, either by the researcher or a professional transcription service and the transcriptions will have all personally identifiable information removed.

Your personal data (address, telephone number) will be kept for 7 years after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason. If you wish to withdraw your data after the interview then we will do so if possible. However, if the data has already been analysed and used in written reports or articles then we will no longer be able to do so.

What will happen to the results of the research study?

The results of the interviews will be written up as part of the lead researcher's PhD thesis and in articles submitted to peer reviewed journals. The interviews will also be used to inform the design of a peer mentoring service to be tested as a further part of the PhD project.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is part of a PhD project being funded jointly by The United Kingdom Occupational Therapy Research Foundation, the Fighting Stroke charity and the Nottingham Hospitals Charity.

Who has reviewed the study?

All research in the University of Nottingham is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Faculty of Medicine & Health Sciences (FMHS) Research Ethics Committee.

What if there is a problem?

If you have a concern about any aspect of this study, you should contact the researcher by email at r.morris@nottingham.ac.uk. The full contact details of the research team are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you should then contact the FMHS Research Ethics Committee Administrator, c/o The University of Nottingham, School of Medicine Education Centre, B Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH. E-mail: **louise.sabir@nottingham.ac.uk**.

Further information and contact details

PhD researcher

Richard Morris
The University of Nottingham
Division of Rehabilitation and Ageing
School of Medicine
Room B108, B Floor, Medical School
Queen's Medical Centre
Nottingham NG7 2UH
Tel: 0115 82 30274
Email: **r.morris@nottingham.ac.uk**

Lead supervisor

Associate Professor in Rehabilitation Research (Long Term Conditions)
Division of Rehabilitation and Ageing
B102, School of Medicine
Queens Medical Centre
Nottingham NG7 2UH
Tel: 0115 823 0226
Email: **kate.radford@nottingham.ac.uk**

Appendix 8: TBI Interviews Topic Guide

About you and your traumatic brain injury - key issues

1) Can you tell me about your brain injury? (e.g., what happened? when? Reiterate that the ppt doesn't have to talk about anything they aren't comfortable with.)

2) What is/are the main issue(s)/problems for you now?
3) What coping strategies do you use to manage these issues?
4) How do these issues affect your life? In terms of:
    - Looking after yourself
    - Getting around

I would now like to ask you about how you view yourself before and after your injury:

1) How would you describe yourself and your outlook on life before your injury?
2) How would you describe yourself and your outlook on life now?
3) Has the brain injury changed you? How?

I would like to ask you a bit more about your hobbies and interests to find out what you did in your free time before your injury and what you do now:

1) Before your injury, were you involved with any social activities? (Provide prompts if needed – meeting friends, visiting family, going to the pub, going for meals with friends/partner, choir, holidays, etc.).
    - What activities?
    - How often and when?
    - With whom?
    - How were these organised?
2) Before your injury, did you pursue any leisure or sporting activities? (Provide prompts if needed – sports, exercise, reading, chess, dancing, playing an instrument, etc.).
    - What?
    - When and how often?

- With who?
- How were these organised?

3) After your injury, did you carry on any or all of these activities?
   - Which ones?
   - How long after the injury did you resume the activities?
   - What factors motivated you to resume the activities?
   - What problems or obstacles caused you to stop activities after the injury?
4) Have you started any new activities since your injury and what are they?
   - How did you develop any new interests?
   - How long after your injury did you start?
   - What other people (friends/therapy team/Headway group) are involved?
   - What motivated you to pursue the new activities?
   - What problems or obstacles have you had to overcome to pursue your new interests? (If not, why and if so, how?)
   - What or who were the main factors in getting started with new activities?
5) What do you find most rewarding about your social and/or leisure activities?
6) Do you think social and leisure activities are important for people after brain injury?
   - Why?
   - Do you think such activities help with other aspects of recovery?

Opinions on re-engagement support and peer mentoring:

1) Would you have liked any support to encourage you to resume your social and leisure activities, or pursue new ones, after your injury?
   - If so, what kind of support would you have wanted?
   - How long after your injury would you have wanted the support?
   - Who do you think such a support service should be funded by (NHS; social services; charity; or patients)?

2) Do you think it would be a good idea to have someone who has experienced brain injury themselves to help someone who has recently had a brain injury to participate in social and/or leisure activities?
    - If so, do you have any ideas about how this support could be delivered? How would the project work in your opinion?
    - What kind of support would the mentor provide? Information? Activities? Socialising?
    - How would the partners be matched?
    - How long after injury should the partnership be made?
    - How would you describe such a project to other people?

3) I am not asking you to do this, but given the opportunity would you be interested in helping someone else to engage in social and leisure activities?

4. Explore additional issues raised by people with brain injury:

1) Are there any issues or ideas that you would like to raise that we haven't discussed so far?
2) Are there any issues or ideas that we have mentioned before/earlier that you would like to discuss again?
3) Would you be happy for us to retain your contact details for future studies?

Thank the person for their time and contribution.

Appendix 9: Mentor Recruitment Advert

Brain injury mentors wanted for University of Nottingham study

We are looking for people with acquired brain injury (ABI) to take part in a study being conducted at the University of Nottingham.

The study is into peer mentoring after brain injury. This will involve pairing experienced brain injury survivors with people injured more recently.

Each pair will be asked to meet six times over 12 weeks. The mentor will help their partner (mentee) by listening, providing the benefit of their experience, doing activities and helping them to meet simple goals.

Mentors may have any form of ABI (traumatic brain injury, stroke, hypoxia or any other) and should be at least one year post-discharge from hospital.

If you are interested in being a mentor please contact Richard Morris at r.morris@nottingham.ac.uk, 0115 823 0274, or 0780 571 6139, for more information. Or return the expression of interest form which accompanies this advert.

Appendix 10: Expression of Interest Form

Peer Mentoring after Brain Injury

We are conducting a study at the University of Nottingham into peer mentoring after brain injury. We would like to invite up to fifteen people to take part as mentors and up to fifteen to take part as mentees.

If you are interested in taking part and would like to hear more about the study please contact:

Richard Morris
The University of Nottingham
School of Medicine, Medical School
Queen's Medical Centre
Nottingham NG7 2UH
Tel: 0115 82 30274 Email: r.morris@nottingham.ac.uk

Alternatively, please fill in your details in the form below, send it to the contact details above, and a member of the study team will contact you.

Name: Address:

Telephone: Email:

I would prefer to be contacted by: telephone ☐ post ☐ email ☐

Appendix 11: Mentor Information Sheet

To be printed on local headed paper

Participant Information Sheet - Mentors
Final version 1.0: 09.02.18

Title of Study: Peer mentoring for Acquired brain InjuRy Study
Study ID: PAIRS
IRAS project ID: 235597

Name of Researcher: Richard Morris

Introduction

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

This research is part of a PhD project at the University of Nottingham investigating peer mentoring after acquired brain injury (ABI). After a serious brain injury, many people find difficulty returning to activities they previously enjoyed, for example social or sporting activities. Peer mentoring involves partnering two people with brain injury together, so that an experienced brain injury survivor (mentor) can help a more recently brain injured survivor to adapt to life after injury. The mentor could draw on their own experiences to help with the many challenges brain injury presents.

We are particularly interested in whether experienced peer mentors can help people who have suffered a more recent brain injury resume personally valued activities. This is because following a brain injury many people stop doing the things they used to enjoy before their injury. They may also find themselves seeing less of their friends. We want to find out if people with brain injuries who have already overcome these problems can help more recently injured people to meet activity goals and so help them with social activity, quality of life, mood and hope for the future.

We have designed a peer mentoring service by talking to people with brain injuries, carers and experts and by learning from other similar services. We now want to test this service to find out if it is possible to recruit enough people to participate and then keep them involved throughout a 12 week programme. We will ask participants to complete questionnaires before and after the programme, and one interview afterwards, to see whether they enjoyed the peer mentoring experience and whether they found it useful. We may further develop the proposed service in the light of this feedback.

Why have I been invited?
You are being invited to take part because you have a brain injury, are at least one year post-discharge from hospital, aged 18 or over and have adapted well to life after injury. We are inviting up to fifteen participants like you to act as mentors, as well as up to fifteen people more recently discharged from hospital who will be helped.

Do I have to take part?

It is entirely up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. Taking part in the study will not affect any treatment, care or welfare benefits you are already receiving.

What will happen to me if I take part?

If you have self-referred for the project and you decide to take part you will be asked to nominate a current or former healthcare or service provider (such as a rehabilitation professional you have worked with or a Headway service manager) to provide a recommendation of your suitability. If you have already been recommended by such a person then you don't need to do anything further on this.

You will then be invited to attend an informal introductory workshop where potential mentors will have a chance to meet the researchers and discuss the project. If you and the researchers are both happy for you to participate then you will need to read and sign a consent form. The researcher will arrange a time and place for you to do this together in-person, most likely at the introductory workshop. If this isn't convenient for you then you will be given the opportunity to discuss the project with the researcher and ask any questions before signing the form and returning it to the researcher by email or post.

All mentors will be registered as volunteers with the University of Nottingham and will be recruited by the Faculty of Medicine and Health Sciences (MHS). Given the nature of the intervention, all mentors will need to complete a Basic Disclosure and Barring Service (DBS) check..

The researcher will contact you to arrange to conduct an assessment. This will take place at a time and place most convenient for you, which could be at your home or by telephone. The assessment will involve asking you questions to gather information about your age, gender, ethnic background, then assess your level of activity, mood, quality of life and hope for the future. You will also be asked about your reasons for wanting to be a mentor and what you would like to achieve from your involvement. The questions should take approximately 45 minutes to complete.

Within 2-3 weeks of your assessment you will be invited to undertake some training on your role as a mentor. The training is expected to take place at the University of Nottingham and will be relaxed and informal. It will take approximately four hours plus time for regular tea/coffee breaks and lunch. Refreshments will be provided.

You will not be expected to pass any tests. Once the training is complete you will be given a certificate of attendance. The University will reimburse any expenses you incur by attending.

If it isn't possible for you to attend the group training session then we will arrange to conduct the training with you individually at a time and venue convenient for you.

When you have been trained and we have received a clear Disclosure and Barring Service Check, we will then match you with a person with an acquired brain injury who has been discharged from hospital within the last six months. This will be a person who needs help adjusting to the effects of their injury and who can benefit from your experience.

We will try to match you to the person based on factors such as gender (a male if you are a male), interests, the place where you live (so you both don't have to travel too far), the effects of your injury and the goals you both set during the initial assessment. This is so that you both have common ground, you can understand the issues the person is dealing with and can help them achieve their personal objectives.

The researcher will then introduce you to the person you will mentor. This will be done at a neutral venue convenient for you both, such as a local coffee shop. The meeting will be relaxed and informal and you will have the opportunity to discuss the project with each other and with the researcher. The researcher will explain what will be expected of you both during subsequent meetings. The meeting will last approximately 30 minutes – 1 hour.

The researcher will call you after the meeting to discuss it and to ask if you are happy to proceed with the partnership. This will give you an opportunity to decline without having to cause any offence to the other person. You will then be given the opportunity to be paired with someone else if you wish. If you'd like to withdraw from the project instead then that's fine. The other person will also be asked separately if they are happy to continue.

If you are both happy to continue the partnership then you will be asked to meet each other six times over the next 12 weeks (roughly once every two weeks). The researcher will not be present at these meetings. You are encouraged to have these meetings in-person at a public venue, although if that isn't possible on some occasions you can arrange to talk by telephone or video call (e.g. Skype). The purpose of the meetings is to encourage your partner to have a positive outlook, to listen and share experiences, help them towards their goals and to take part in activities. If you just want to talk then the meetings should last approximately 30-60 minutes. If you decide to do an activity together then the length of the meeting will depend on what you do.

You and your partner will be asked to agree a mutually suitable method of arranging meetings in advance. You will be asked to prearrange meetings as early as possible and to confirm the dates and times of sessions with the researcher. If you need to cancel or rearrange a session you will be asked to provide your partner with as much notice as possible.

In order to maintain your privacy you will be provided with a temporary University of Nottingham email address and will be given the option of having a temporary pay-as-you-go mobile phone to use for contacts with your partner.

Activities should be kept simple and not involve anything dangerous. Examples may include going for a walk, going to the cinema, playing board games, shopping, going for coffee, jogging, etc.

You will be required to inform the researcher by text or telephone just before each session starts and when you have returned home.

When the 12 weeks are over you will be asked to complete the assessments again so that we can see if the results have changed. You will also be interviewed about what you thought of the mentoring programme. This should last up to one hour. These interviews will be recorded on an audio recorder and stored securely at the University of Nottingham.

The assessments and interviews can be done at different times if you wish and you can take breaks if you want to. They can be done at your home or by telephone depending on your preference.

Your involvement in the study will end at this point and no more mentoring sessions or assessments will take place. The total amount of time you spend involved in the study from recruitment until the final assessment is estimated to be a maximum of seven months. If you choose to remain in contact with your mentoring partner after this time then that is entirely the choice of you both.

Volunteering registration

All mentors will be considered as volunteers with the University of Nottingham and will follow standard University volunteer recruitment processes. This process will begin when you have consented to participation. Given the nature of the intervention you will need to complete a Basic Disclosure and Barring Service (DBS) check. You will be provided with a pack of information explaining everything you need to know about being a volunteer at the University.

Expenses and inconvenience allowance

Participants will not be paid to participate in the study. All efforts will be made to pay you for any expenses you incur during the study. The Campaign and Alumni Relations Office will provide parking permits should you need to visit campus. They will also provide volunteer stewardship and a thank you from the University for taking part in the study.

What are the possible disadvantages and risks of taking part?

There are risks involved when going out in public and doing activities with a person you don't know very well. However, all precautions have been taken in designing this study to keep risks to a minimum and no dangerous activities are permitted. You will not be asked to reveal to your mentoring partner personal information such as your address, email address or own phone number if you don't want to.

Although unlikely, it is possible that your partner might want to do something you consider risky, tell you something you are uncomfortable with or become reliant on your support. You might even have concerns about their health and wellbeing. You are encouraged to discuss any concerns you might have with the researcher and all efforts will be made to resolve the issues without causing you undue difficulties.

What are the possible benefits of taking part?

The information we get from your participation in this study may help us to understand more about how peer mentoring can help people with a brain injury. We will learn about whether it is feasible to run the service and whether brain injury survivors engage with it and stay involved for the full 12 weeks.

It will teach us about what works well and what doesn't work so well and will also give us an idea as to whether it is likely to be effective. This information will help researchers and clinicians to develop peer mentoring services in the future.

Previous peer mentoring projects have shown that participants found it helpful and enjoyable. Mentors have enjoyed the experience of helping someone else with a brain injury. They have felt valued and have appreciated the opportunity to give something back. Mentored participants have also appreciated the support of someone who has dealt with similar difficulties to themselves.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. The information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Where possible information about you which leaves the site will have your name and address removed and a unique code will be used so that you cannot be recognised from it, however sometimes we need to ensure that we can recognise you to link the research data with your medical records so in these instances we will need to know your name and date of birth.

Audio recordings of interviews will be uploaded to a secure drive on the University of Nottingham server and then deleted from the digital voice recorder. The recordings will then be transcribed to text and the transcriptions will have all personally identifiable information removed.

Your contact information will be kept for 12 months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

If you mention something which raises concerns about the safety or welfare of yourself or anyone else in the project then the researcher will need to discuss this with their chief supervisor. If necessary the issue will be reported to the person's GP, healthcare practitioner or the relevant authorities.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

What will happen to the results of the research study?

The results of the study will be written up as part of a PhD thesis, in articles submitted to journals and in posters and other conference presentations. Plain English summaries will also be written for publication in charity magazines and websites.

We will keep you informed of the results by sending you a plain English summary and also details of any publications.

Involvement of the General Practitioner/Family doctor (GP)

We will inform your GP of your participation. You will be asked for the name of your GP practice so we can write to them.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is part of a PhD project being funded jointly by The United Kingdom Occupational Therapy Research Foundation, the Fighting Stroke charity and the Nottingham Hospitals Charity.

Who has reviewed the study?

All research in the University of Nottingham is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Nottingham Research Ethics Committee 2.

What if there is a problem?

You will be assigned a member of the research team who you can talk to about the project and how it is going. If you have any problems or concerns you can discuss it with the researchers during these discussions or contact us at any time. The full contact details of the research team are given at the end of this information sheet.
If you remain unhappy and wish to complain formally, you should first contact your local Patient Advice and Liaison Service (PALS) (if you have been recruited from within the NHS). Contact information for your local PALS is available from your GP or local hospital. You may also wish to contact the head of the School of Medicine, Professor Tony Avery (full contact details below).

Appendix 12: Summary of Mentor Training

Introductory Day

Participants were all asked to sign a register and were provided with a mentor handbook designed by myself and which contained key information relating to the role of a mentor as well as space to make notes and to record details of mentoring meetings. They were also reminded about the steps towards attaining a DBS check and provided with full written details of the process. Anyone having difficulties with the form was told that there would be time at the end of the session for the researcher to help them.

Participants were also provided with expenses forms to claim for travel costs; paper copies of the workshop slides; an agreement form for University volunteers; a volunteering toolkit with details of all their entitlements as official volunteers of the University; copies of the study participant information sheet for mentors; a consent form; paper and pens. A full set of Headway booklets and factsheets were also provided.

Participants were asked to arrive at around 9.40 am for a 10 am start. Tea, coffee, rolls and biscuits were provided by the catering service at the venue. A projector was used to present information on slides for easy viewing for all and to provide details and reminders of all tasks required of participants. An easel and pad were used to write ideas from discussions and brainstorming activities.

The schedule for the introductory training day was as follows:

9.40–10 am: Arrival and Refreshments

10 am: Welcome and Introduction

10.15 am: Sharing Experiences

Participants were split into pairs and asked to take a few minutes each to talk about aspects of how their life had changed after their brain injury and activities that had helped them. They then took it in turns to tell the rest of the group one or two key things about their partner and one or two activities their partner liked doing or thought it would be good to do with a mentee.

10.40 am: Characteristics of a Mentor

Participants were split into pairs again. They were asked to discuss what characteristics a mentor needs and how these can be developed in potential mentors. Each pair was provided with paper and pens and asked to write down one list of helpful and desirable characteristics and another list of unhelpful and undesirable ones. They were then asked to feedback to the rest of the group one pair at a time.

11.10 am: Break

11.25 am: Becoming a Mentor

I provided an overview of the expectations of a mentor and the support that will be provided.

11.50 am: Expectations and Concerns

This was a combination of group discussion between everyone and a question and answer session for the researcher. Everyone had the opportunity to ask questions and voice any concerns about involvement.

12.10–12.30 pm: Concluding Issues

Main Training Day

The second training day was longer than the first, with less introductory information about the study and more focus on specific detail of the requirements of the study, and the skills and characteristics of a mentor. It took place a week after the first session, in the same room at the Lakeside Arts Centre. The participants who had indicated their desire to attend were sent reminder emails ahead of the session and asked to bring along the mentor handbook that they received last time. Spare copies of the handbook were provided on the day for anyone who had not brought theirs. All other equipment, handouts, and information resources provided at the first training day were provided again.

The schedule was as follows:

9.30–10 am: Arrival and Refreshments

10 am: Recap of Introductory Session and Key Issues

10.20 am: The Mentoring Programme

I talked through the mentor handbook and elements of the information sheet, explaining and clarifying key elements such as expectations, making arrangements, setting goals and doing activities.

10.40 am: Common Difficulties Following Brain Injury

This was a group discussion where participants were asked to suggest common effects of brain injury and the difficulties that these can present in everyday life.

11.20 am: Break

11.35 am: Participation in Personally Valued Activities

Participants were asked to split up into pairs for this activity. The pairs were asked to take it in turns to act as mentor and mentee. The concept was for the one playing the mentee to think back to the time after their injury and talk about a couple of activities they would have liked to do and discuss how a mentor could have helped. The mentor's job was to try to think of ways they could have helped and to consider their own suitability for helping with such activities. After one member of each pair had taken the role of mentee, each pair spoke to the whole group about their discussion before changing mentor/mentee roles and doing the same again.

12.20 pm: Lunch

12.50 pm: Mentoring Goals and Motivation

This was another pairwork activity. The idea was to talk to each other about reasons why they wanted to get involved in the project and become a mentor. This included what they would like to achieve, goals, and how they would like to help.

1.30 pm: Challenges of a Peer Mentoring Relationship–Problems, Risks and Safety Issues

Participants were again required to split into pairs and discuss potential problems they anticipated may occur in a peer mentoring relationship (from any perspective). I gave each pair a few minutes for discussion and then asked each pair to take it in turns to feedback to the rest of the group.

2.10 pm: Next Steps, Wrap-up and Questions

Everyone had the opportunity to ask further questions and make sure they had everything they needed. Those who wanted to, and hadn't done so already, could sign and return their consent forms. I gave out personalised certificates for successful completion of the training to everyone and also gave out feedback forms for evaluation of main training day and the introductory workshop.

Evaluation

Evaluation forms were provided, and participants were asked to complete one each at the end of the second training day. The evaluation forms presented the following statements:

- The sessions were well structured.
- The sessions were enjoyable.
- The training has made me feel well-equipped to be a peer mentor.
- I feel that the training covered everything I need in order to be a peer mentor.
- The trainer conveyed the topics well.
- The handouts were useful.

One of the following options was selected for each statement: Not applicable; Strongly agree; Agree; Neutral; Disagree; Strongly disagree.

Free text spaces were also provided for responses to the following:

- Please tell us about any particular topics or exercises which you found useful.
- Please tell us about any particular topics or exercises which you didn't think were useful.
- Please tell us about any way you think the training could be improved.

Appendix 13: Post-Intervention Topic Guides

Mentee/Mentor/Carer Topic Guide

The wording of the questions was adapted for each group.

Personal Experience with the Programme

1. What were your expectations before you started the mentoring programme? [BCW-Capability, Motivation]/ [ICF- Activities and participation]
    - Did you make any plans to do things? If so what plans?
    - Did all the plans happen? If not, why not?
    - Was there any activity that you were expecting to do that did not happen?

2. Did you meet your mentor six times over 12 weeks? [BCW- Capability, Opportunity, Motivation]/ [ICF- Part 1: Functioning and Disability and Part 2: Contextual Factors]/ [Key findings S&G- programme characteristics

    If yes:

    - What made you continue making plans with the mentor?
    - If not, why not?
    - Why did you stop making plans with the mentor?

3. How would you describe the nature of your relationship with the mentor? [BCW-Opportunity, Motivation]/ [ICF- Environmental Factors]
    - What was the most useful thing about having a mentor?
    - Can you think about how the mentor could have been more helpful/ useful? [Key findings report- Mentor traits]
    - If your relationship with the mentor was not useful, what do you think would have helped you? / what would you have wanted instead? [Key findings S&G- elements of risk]
    - From your experience in the programme, what do you consider the key qualities of a mentor to be? [Key findings report- Mentor traits]

Programme Attributes

4. Did having a mentor/ did the mentor help you achieve the goals you set at the beginning of the programme? [BCW-Capability, Motivation] [ICF- Activities and Participation & Environmental Factors]
    - How did the mentor help you achieve these goals?
    - Have you learnt anything from the programme? (e.g. stand up for yourself, get out more?)

- What was the most useful aspect of the programme/ having a mentor?

5. If the mentoring programme did not help you achieve your goals, why was that? [BCW-Capability, Opportunity, Motivation]/ [ICF- Part 1: Functioning and Disability and Part 2: Contextual Factors]

-What could have been done to achieve your goals?

-Is there anything that might have helped you achieve your goals? [Key findings S&G- programme characteristics]

-What was not useful/unhelpful? [Key findings S&G- programme characteristics]

6. We said at the outset of the programme that this may not work for everyone – was there anything that didn't work well for you? [BCW- Capability, Opportunity, Motivation]/ [ICF- Part 1: Functioning and Disability and Part 2: Contextual Factors]/ [Key findings S&G- elements of risk]
    - In terms of the way it was set up e.g. in (the training) and or the pairing/ matching?
        - Would you have liked to swap mentors?
        - If it didn't work out – why was that?
    - In terms of what happened next, i.e., the meetings with the mentor, was there something that didn't work well for you?
    - In terms of support from the researcher, did you need any extra support? [Key findings S&G- safety net]
        - What kind of support?
        - Why did you need the extra support?
        - Did you receive any extra support from the researcher?

Future Implementation

7. Going forwards, should this programme be available for everyone with a brain injury? [BCW- Opportunity]/ [ICF- Environmental and Personal Factors]
    - If not, why not?
    - We aim to make this programme available for everyone with acquired brain injury. If we improve the programme with the feedback of different people to create a final and successful programme, it may need to be linked to an organisation or a service to roll it out. [Key findings S&G- existing services]
        - Who should provide it?

- Who should coordinate it? (E.g. health services, charities, private sector)
- Do you have any thoughts on who (which organisation) that should be?
- What would you consider to be the ideal characteristics or features for this type of programme? [Key findings S&G- programme characteristics]
    - What would you consider as relevant or successful achievements for this type of programme (key outcome)? [Key findings S&G- Success criteria]

8. Apart from the topics discussed, can you think of anything else that might make this programme better? [BCW-Opportunity]/ [ICF-Activities and participation, Personal Factors]

Healthcare Provider/Recruiter Post-intervention Interview Questions

1. Have you ever run peer mentoring type services for clients before, or been involved in such services?
2. What were your expectations and impressions of the peer mentoring programme?
3. Do/did you think peer mentoring is/ would be particularly useful for any specific groups of brain injured clients? Think about factors including:
    - Particular form of brain injury
    - Length of time after brain injury
    - Effects of injury
    - Individual circumstances
4. Is there anything that made you wary of referring clients to the peer mentoring project, even if they met the study eligibility criteria? Think about factors including:
    - Particular form of brain injury
    - Length of time after brain injury
    - Effects of injury
    - Individual circumstance
    - Safety
    - Support
    - Conflict with your services
    - Uncertainty about the intervention
    - Compatibility with partners
    - Feeling protective for patients
5. Did you have ongoing discussions with colleagues about referring clients to the project?
6. How do you think peer mentoring should fit in with existing services? Should it be embedded within them or stand separate?
        - Safety
        - Key outcomes
        - Monitoring
        - Your own services/clients
        - Future implementation
7. What do you think are the key outcomes of a peer mentoring service?
8. How do you think the programme could be improved in future?
9. Do you have any thoughts on how recruitment could be improved?
10. Are there any further comments you'd like to make?

Appendix 14: Intervention Interview Themes

Mentor, Mentee, and Carer Interviews

Theme One: Practical issues for meetings and activities

Sub-themes	Definition	ICF and BCW constructs and components	Example quotes
Physical and sensory impairments	The impact of issues such as mobility difficulties and sensory impairments on participating in activities.	ICF: Body functions (impairments); Activity (limitations); Participation (restrictions) BCW: Capability	"Mum is quite frail and she's not very strong on her feet and I just suggested that they went for a coffee each time rather than doing something that might have tired mum out or something that she wouldn't have been happy doing." Carer One
Making arrangements	Issues related to the organisation and scheduling of meetings.	ICF: Body functions (impairments); Activity (limitations); Participation (restrictions); Environmental factors BCW: Capability; Opportunity; Motivation	"But that's why we didn't meet as often because she couldn't get into the city because of her babysitting issues and I couldn't get into the city because I can't physically go anywhere without assistance. So it became difficult to meet up because of the locality that we both had." Mentee Five
Motivation	The influence of intrinsic and extrinsic motivation to attend mentoring sessions and participate in activities.	ICF: Body functions (impairments); Activity (limitations); Participation (restrictions) BCW: Motivation	"No, we just went for coffee and went round a garden centre. That's what she wanted to do and that suited me too." Mentor Four
Transport	Barriers and facilitators to travelling to and from meetings.	ICF: Environmental factors; Body functions (impairments); Activity (limitations); Participation (restrictions) BCW: Capability; Opportunity; Motivation	"[Mentee] can't walk too far, so it had to be somewhere that was near a bus route...So, yeah, it took a lot of planning...We live in different areas of [town] and neither of us drive, so it was all like public transport and yeah, it was just too much for him to do it." Mentor Three
External circumstances and commitments	Factors in participants' lives which impacted on their involvement in the project.	ICF: Personal factors; Environmental factors BCW: Capability; Opportunity	"Because he was working a bit as well and I do a bit of part time work, as well, so it was just trying to fit it all around the commitments…We didn't manage all the sessions because he went back to work." Mentor Three

Number and duration of the meetings	How participants felt about the number of meetings they were intended to have, how many they actually had, and the length of the meetings.	NA	“I think the six to eight sessions is also really good, that’s good timing.” Mentor Four "It wasn’t too many and it wasn’t too few." Carer One

Theme Two: Benefits of peer mentoring

Sub-themes	**Definition**	**ICF and BCW constructs and components**	**Example quotes**
Impartiality	The benefits of talking to somebody who is impartial and not a family member or close friend.	ICF: Environmental factors; Personal factors	“Because, you know, if you want to cry and be so angry and upset about it, it’s hard to do that sometimes with your family and friends because you don’t want to upset them. And, actually, having someone who you don’t know, that can be really powerful, I think.” Mentor Three
Shared experience	The benefits of talking to somebody who also has a brain injury and has been through similar experiences of recovery.	ICF: Environmental factors; Personal factors	"I found it helpful to talk to somebody, obviously, that had experienced similar and was going through similar things. It was nice just to talk to somebody who felt frustrated sometimes with other people who don't understand.” Mentee Two
Impact on mentors	The benefits mentors derived from their participation.	ICF; Participation; Personal factors BCW: Opportunity	"It was just a case of I wanted to help out. I didn't have this opportunity when I had my TBI…It makes me feel good that I can give something back." Mentor One
Individualised support	The capacity of peer mentoring to be tailored to the specific needs of individuals.	ICF: Activity; Participation; Personal factors BCW: Capability; Opportunity; Motivation	“So I would say surely that’s got to be an individual…In the end, they’ve just got to feel happy and better about their situation, whatever they think is important to make better and change, to improve. For people with different brain injuries, that will be very different, won’t it?” Mentor Four
Social contact	The social interaction which mentoring provided.	ICF: Participation; Activity	“The most important thing from mum’s point of view, or one of the most important things, is it’s additional company for her. Because, you know, she’s in a flat on her own…it’s additional company, isn’t it, and that

			mental stimulation is really important.” Carer One

Theme Three: Training and support needs of participants

Sub-themes	Definition	ICF and BCW constructs and components	Example quotes
Training and information	Opinions of the mentor training and any additional training requirements. Also, views on the information participants received and further information they would have liked.	ICF: Environmental factors; Participation BCW: Capability	“I met a lot of people who had similar things, a range of brain injuries and that was really, really useful. And [the] training was really, really useful.” Mentor Four
Support from the researcher	Opinions of the support participants received from the researcher and further support they would have liked.	ICF: Environmental factors; Participation BCW: Capability	“[The researcher] was very good, [the researcher] was fantastic about always following up, and listening, and really having a lot of time and I can’t praise him enough for that. That was really supportive.” Mentor Three
Mentor-to-mentor support	Opinions relating to support mentors would have liked from other mentors on the project.	ICF: Environmental factors; Participation BCW: Capability	"It would have been nice to have more contact with some mentors, sort of while it was going on…see how they were getting on with theirs…At the very end, it would be really, really nice to meet up with all the other mentors and debrief." Mentor Four

Theme Four: Suitability and compatibility

Sub-themes	Definition	ICF and BCW constructs and components	Example quotes
Type of injury and effects of injury	The causes of participants’ brain injury (e.g., TBI and stroke) and the short-term and long-term effects (e.g., memory loss, personality change and physical impairments). Relates to how the similarities and differences between mentors and mentees affected their compatibility.	ICF: Body functions (impairments); Body structures (impairments); Activity (limitations); Participation (restrictions)	"She didn't understand my situation and I couldn't fully appreciate and understand hers. I mean, mine was an injury to the brain caused by a stroke which had physical effects. Her injury is more mental. Therefore, we weren't

			on the same page regarding that." Mentee Five
Personality	The importance of partners getting on well together and having compatible personalities.	ICF: Personal factors	"We got on. If you don't get on with the person who you're doing it for then…that's a problem, isn't it?" Mentor One
Traits of a good mentor	The personality traits and qualities considered important for someone to be a suitable mentor.	ICF: Personal factors BCW: Capability	"[Mentor] is a very good listener - she's a very attentive listener as well" Carer One
Timing for mentees	How the time since a mentee's injury, and the progress of their recovery, affect their suitability for peer mentoring.	ICF: Body functions (impairments); Body structures (impairments); Activity (limitations); Participation (restrictions); Environmental factors BCW: Capability	"I think when it started, it took quite a long time to organise. It took over six months before I actually got a mentor and, by then, I'd started to go out a little bit anyway. So it was a bit late, really." Mentee Two

Healthcare Provider Interviews

Theme One: Attributes of peer mentoring

Sub-themes	**Definition**	**ICF and BCW constructs and components**	**Example quotes**
Shared experience	Support from a brain injury survivor who has first-hand experience and knowledge of the challenges.	ICF: Personal factors; Body functions (impairments); Activity (limitations); Participation (restrictions) BCW: Capability	"In principle, I like the idea of it, and I can certainly see that, you know, speaking to somebody who's been through a shared experience would be beneficial." HCP Five
Impartiality	Support from somebody who is not a friend or family member and has no personal involvement in the mentee's prior life.	ICF: Personal factors BCW: Motivation	"I think sometimes they just need somebody to speak to who is not involved. Because sometimes relatives are too close and the patient doesn't want to tell them because they don't want to upset them. Sometimes professionals, they think, 'it's just a job to you', spouting medical jargon." HCP Four
Individualised support	Support tailored specifically to the needs of the mentee, enabling them to aim for individual goals,	ICF: Body functions (impairments); Activity (limitations); Participation	"If you've…somebody like 'well we want to go for a game of golf

	and do activities they enjoy at times and places suited to them.	(restrictions); Personal factors BCW: Capability; Motivation	or go to the cinema', you've got more scope to do those individualised things rather than a group." HCP Two
Social and leisure participation	Meeting other people and/or taking part in enjoyable activities.	ICF: Activity; Participation	"Social inclusion and community activity doesn't come to the top of the list with statutory rehab services. So it could certainly supplement what people are offered…taking people out for coffees and getting to the gym and getting them swimming and building their confidence to walk outside." HCP Five
Potentially negative influences	The negative aspects of influence from a peer mentor. For example, demonstrating inappropriate behaviour, or providing a model of recovery which is unrealistic or demotivating.	ICF: Body structures (impairments); Body functions (impairments); Activity (limitations); Participation (restrictions) BCW: Capability; Motivation	"Being paired with someone that's still severely impaired 10 years down the line, yeah, I can see how that would freak people out…[some] people think oh that could be me. I might stay in this state." HCP Five

Theme Two: Recruitment issues—patients

Sub-themes	**Definition**	**ICF and BCW constructs and components**	**Example quotes**
Behavioural issues	Difficult behaviour, such as disinhibition, embarrassing outbursts, anger management problems, etc., which professionals felt could make patients unsuitable for mentoring.	ICF: Body functions (impairments); Personal factors BCW: Capability	"Are they a safe person to match with somebody else and leave on their own to do that and can they be managed or have they got, you know, behavioural issues, anger issues…" HCP Two
Physical issues	Mobility problems which would make transport to meetings and participating in community activities difficult.	ICF: Body structures (impairments); Body functions (impairments); Activity (limitations); Participation (restrictions) BCW: Capability	"…physically can they get there because if you're asking people to meet people can they actually get somewhere safely so can they leave the house, safely." HCP Two

Cognitive issues	Problems with memory, attention, organisation and problem-solving, which could make it difficult for someone to cope with participation in the project.	ICF: Body functions (impairments); Activity (limitations); Participation (restrictions) BCW: Capability	"…can they organize themselves safely not get lost on the way to somewhere, you know, so those safety things would be high in your mind." HCP Two
Insight and acceptance of condition	Lack of understanding and awareness of the effects of the brain injury on a person's own life, which could impair them from engaging with the project and learning from a mentor.	ICF: Body functions (impairments); Activity (limitations); Participation (restrictions) BCW: Capability	"So, they've got to have a level of awareness and insight. People have got to be willing to sort of change and listen." HCP Four
Time since hospital discharge	The time elapsed since discharge from hospital after the injury. This was set at <12 months for people to be eligible as mentees in the project, but some patients were not considered ready to participate at this stage.	ICF: Personal factors BCW: Capability	"When I think about some of the current caseload, perhaps, by the time they're sort of ready to engage as a mentee I wonder if they're then past that twelve months post-discharge." HCP Three
Lack of willingness to participate	The lack of sufficient interest and motivation of some patients to go to the necessary lengths to enrol in the project.	ICF: Personal factors BCW: Capability; Motivation	"I think on a one-to-one you say they're running this study, are you interested, they say oh yeah I'm dead up for that. But, actually, when it comes to sitting down and reading things and giving consent, it goes [indicates overhead]." HCP Five

Theme Three: Recruitment issues—clinicians

Sub-themes	**Definition**	**ICF and BCW constructs and components**	**Example quotes**
Referral to an external project	Willingness of clinicians to refer clients to services and projects outside of their influence and control.	ICF: Environmental factors; Personal factors	"I was a bit unsure. I know there were sort of support mechanisms in place, but how much clinical input there was from, for example, psychologists or people if issues came up." HCP One

Client availability	Number of clients in a service's caseload who are eligible for the project.	ICF: Environmental factors; Personal factors	"I don't think we had that many at all, because our referrals are quite staggered…so it's not like as a service we get loads of new referrals each week." HCP One
Clinician judgements	Judgements made by the clinicians about a client's suitability for the project.	ICF: Body structure (impairments); Body function (impairments); Activity (limitations); Participation (restrictions); Environmental factors; Personal factors	"Maybe as clinicians rightly or wrongly we're maybe making a judgement on…can they sort of take on something at that time?" HCP One
Clinician engagement	Attention and time given by clinicians to identifying, approaching and referring clients to the project.	ICF: Environmental factors; Personal factors BCW: Motivation	"I think you probably could have got more. I think there's a bit of a drive and then it wanes and you do something else." HCP Two